The White House Conference on Handicapped Individuals

SPECIAL CONCERNS

State White House Conference Workbook

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The White House Conference on Handicapped Individuals

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Dear State White House Conference Delegates:

It is with admiration and appreciation that we welcome your participation in this State White House Conference.

From the beginning of White House Conference activities, we have placed great importance on the deliberations of State Conferences.

The recommendations emanating from your Conference will form the basis of actions at the White House Conference itself.

We encourage each delegate to use this Conference to impact in new ways on State and local governments, the private sector and the Federal Government to bring greater independence, dignity and full participation into community life for all mentally and physically handicapped individuals.

We wish you great success in an endeavor that will benefit handicapped individuals for years to come.

Sincerely,

Henry Viscardi

Dr. Henry Viscardi, Jr.
Chairman, National Planning
and Advisory Council

Jack F. Smith

Jack F. Smith
Executive Director

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OVERVIEW
THE WHITE HOUSE CONFERENCE ON HANDICAPPED INDIVIDUALS

The mission of the White House Conference on Handicapped Individuals is comprised of three goals:

-- to provide a national assessment of problems and potentials of individuals with mental or physical handicaps;

-- to generate a national awareness of these problems and potentials; and

-- to make recommendations to the President and Congress which, if implemented, will enable individuals with handicaps to live their lives independently, with dignity, and with full participation in community life to the greatest degree possible.

The White House Conference on Handicapped Individuals was authorized with the passage of Public Law 93-516. Title III of that law stated that there were some "seven million children and at least twenty-eight million adults with mental or physical handicaps," and that "it is of critical importance to this Nation that equality of opportunity, equal access to all aspects of society and equal rights guaranteed by the Constitution of the United States be provided to all individuals with handicaps."

Toward that end, the President was authorized to call a White House Conference which would "develop recommendations and stimulate a national assessment of problems, and solutions to such problems, facing individuals with handicaps." Announcement of the Conference was made by the President on November 22, 1975, with the date for the National Conference set for December 1976, and then changed to May 1977.

The result of the White House Conference should be new advances by and for handicapped individuals, with this movement picking up momentum following the publishing of recommendations. If the recommendations and implementation plan are to be instrumental in generating that momentum, they must emerge as a consensus from a broad base of support. The purpose of the National Conference is to become a focal point for such a consensus.

For the National Conference to be successful, it must be representative of the same base of support which is needed later in carrying forward the recommendations. First, it is especially critical that the energies and ideas of handicapped people be engaged. At least 50 percent of the State delegates to the White House Conference will be handicapped, and 25 percent, parents or guardians of handicapped individuals. Professionals who provide services and others from business, labor and government who are interested in the problems of the handicapped will attend.

The criterion for a successful Conference also includes the opportunity for free participation by the delegates. At the same time the deliberations must be focused on what already has been defined as key issues.

To meet the goal of national awareness, the Conference and the issues must have good public visibility. Since the National Conference is necessarily limited in the number who can participate, it is well to include as many interested individuals as possible in defining the issues and providing the preliminary national assessment leading up to the National Conference.

Among the ways to secure this greater involvement and to channel needs and recommendations on issues to the delegates at the National Conference is through meetings at the state and local levels. This approach will also assure that attention is drawn to the actions that can be taken at the local and state levels to assist handicapped people in meeting their goals. The White House Conference activity should focus on recommendations for action by all sectors at all levels of national life, and not just by the Federal Government.

Our strategy, then, is to encourage the sponsorship, locally, of forums at which primarily handicapped individuals can introduce their views into the Conference process. At the state level (including the District of Columbia and the territories), preliminary White House Conferences will be held as intended by Congress. Reports of findings from both these types of events will be channeled into the National Conference for review and discussion prior to final recommendations.

In order to assure that local and state reports lend themselves to summarization for National Conference delegates and for the final report, a standard format has been developed for reporting. In addition, "awareness papers" have been written by experts in the field and given to leaders of State Conferences. Five broad areas cited by Congress are covered: health, educational, social, economic, and special concerns. These papers have initiated work on the national assessment goal. They define the barriers faced by people with

various handicaps and review what we already know about how those barriers can be overcome or minimized.

To get the kind of involvement necessary to generate national awareness foreseen in the Conference goals, we will enlist every major national organization and government agency to take an active part in the Conference activities before, during, and after the National Conference itself. Members of Congress and their staffs will also be involved to maintain their support.

In support of all these activities, and overlaying them in pursuit of the national awareness goal, will be a public affairs program.

With sufficient administrative support, we believe this strategy can be implemented and will be successful in creating the climate and the specific steps necessary to enable handicapped individuals to realize their potentials as contributors to American life.

The final White House Conference report to the President will offer very specific solutions to problems facing individuals with handicaps, and an implementation plan to the President and Congress will insure follow-up of Conference recommendations.

DEFINITIONS

1. Alternate -- An appointee from a State as an observer to the National White House Conference who may, at the appointment of the State White House Conference Director, fill a vacancy as an official delegate when an official delegate is unable to attend.

2. Awareness Paper -- Topical material, applicable to an assigned subject area, researched and organized in order to establish the foundations for informed Conference discussion and resolution of the vital issues affecting all handicapped persons at the local, State and National levels.

3. Conference Plan -- The three major goals of the Conference and the objectives and strategies necessary in order to achieve these goals.

4. Consumer -- A handicapped individual or a parent, guardian, sibling, or spouse of a handicapped individual.

5. Delegate -- A representative to the Conference who is the only Conference participant to hold voting privileges.

6. Delegation -- A group of Conference delegates selected to represent other individuals at the National Conference.

7. Goal -- A long-range objective or target stated in broad, general terms.

8. Grant Application -- Forms provided by the White House Conference to the states which must be submitted for all grants awarded under Title III, White House Conference on Handicapped Individuals Act.

9. Handicapped Individual- Any person who a) has a physical or mental impairment which substantially limits one or more of such person's major life activities; b) has a record of such an impairment; or c) is regarded as having such an impairment.

10. Issue -- A question - resolvable in two or more ways - formulated for the purpose of determining what broad policy or action should be taken to move toward a specific, goal-oriented objective.

11. Level of Participation- Includes, but not necessarily limited to: 1) delegates; 2) observers.

12. Local Forum -- A public meeting, radio program or television program involving open audience discussion related to the problems and potentials of physically and mentally handicapped individuals and suggested solutions to those problems, the results of which to be channeled into the State and/or National Conferences for review and discussion prior to final recommendations.

13. National Conference -- A meeting of official delegates from each state, members of the National Planning and Advisory Council, delegates-at-large, and observers, for the purpose of discussing the issues, developing and refining recommendations and plans for action to be made to the President and Congress, which, if implemented, will enable individuals with handicaps to live their lives independently, with dignity, and with full participation in community life to the greatest degree possible.

14. National Planning and Advisory Council -- A Council appointed by the Secretary of Health, Education, and Welfare composed of 28 members, of whom not less than ten shall be individuals with handicaps appointed to represent all individuals with handicaps,

and five shall be parents of individuals with handicaps appointed to represent all such parents and individuals, to provide guidance and planning for the Conference.

15. Observer -- A person identified as holding some special interest in the work and objectives of the Conference who may attend the Conference, but is nonvoting and nonparticipating.

16. Program Guidelines -- A set of focused, strategically feasible principles and plans for action to provide directions for Conference activities.

17. Recommendation -- A proposal for specific action designed to implement policies and to move toward goals.

18. State -- Includes the several States, the District of Columbia, the Commonwealth of Puerto Rico, Guam, American Samoa, the Virgin Islands, and the Trust Territory of the Pacific Islands.

19. State Conference -- A formal meeting to interchange views among individuals with handicaps; members of their families; representatives of Federal, State and local governments; professional experts; and members of the general public recognized by individuals with physical or mental handicaps as having knowledge about problems affecting their lives, for the purpose of considering all issues related to the mission of the Conference, and shall be required to address specific issues as outlined by the White House Conference on Handicapped Individuals.

20. State Director of White House Conference Activities -- The person(s) appointed by the Governor to direct and coordinate White House Conference activities at the State level.

21. State Grant	-- Sum appropriated by Public Law 93-516 to be made available to each State through the Secretary of Health, Education, and Welfare, upon application of the chief executive, in order to assist in meeting the costs of that State's participation in the Conference program, including the conduct of at least one Conference within each such State.
22. White House Conference on Handicapped Individuals	-- Authorized, by Public Law 93-516, as a joint effort between the Federal Government and the States and their citizens to develop recommendations and stimulate a national assessment of problems, and solutions to such problems, facing individuals with physical or mental handicaps.
23. White House Conference Program	-- All activities at the local and State levels, related to the overall goals of the Conference, the results of which may be channeled into the National Conference for review and discussion prior to final recommendations.

ROLES AND RESPONSIBILITIES OF DELEGATES TO THE STATE CONFERENCES

State Conferences must address and propose recommendations for at least two issues (see Section F, Summaries of Awareness Papers and Issues) for each of the 25 Conference topics (see Section E, White House Conference Topics).

What is an issue?

An issue is defined by the White House Conference as:

> "A question--resolvable in two or more ways-- formulated for the purpose of determining what broad policy or action should be taken to move toward a specific, goal-oriented objective."

This is the formal definition of an issue. But what does that mean to you, as a State Conference delegate, in the generation of issues and the subsequent recommendations which will follow these issues? It will be the purpose of this paper to help you learn the format for formulating issues and resolutions because, if you do so, you will assure that your state has been adequately represented in formulating the National White House Conference agenda.

How does that work? Remember that the agenda of the National Conference is based on the issues and the resolutions submitted by the States.. When your State's Conference report is submitted to the White House Conference (within 30 days after completion of the Conference(s)), the staff members will take it apart, issue by issue, and synthesize it with all other State inputs to reduce it to the fewest common issues, plus all the unique issues that arise. The National Conference agenda will then be composed of meetings which will consider all these issues and their recommendations, and the National DELEGATES will vote on which issues and which recommendations should be addressed in the final implementation plan of the Conference. So, to assure that your State's input is adequately handled, it is extremely important that your issues and your recommendations be clearly understood, and consistent in format to the reports of issues from other States. If they are not, the information could be misunderstood, misinterpreted, and misplaced.

An issue might look like the following

> In a time of competition for scarce public funds, what innovative approaches can be taken by education administrators to assure maximum utilization of available dollars?

What makes this a good issue? It is open ended. You should be able to think of at least two good answers. You will probably be able to think of clue words that could suggest whole implementation strategies, clue words such as "monitoring systems," "voucher systems," "management training," "parent monitoring," "cost benefit studies," "legislative lobbying," etc., etc. The issue should be, in fact, a stimulus for brainstorming because it is so open ended.

And notice that the answers, which you brainstorm as clue words, are broad--they encompass many actions--they suggest systems that will produce measurable results. That also makes it a good issue, because the clue words and thoughts stimulated by the question imply broad actions that should be taken to move toward a goal-oriented action.

What is a goal-oriented action? In the above issue, that goal-oriented action is easily inferred--the goal is to secure more public funds for more services of education to handicapped individuals through increased efficiency. You can probably measure that, you know, by counting dollars and individuals served through education.

So, the issue is good because:

(a) it succinctly restates the problems (this is optional, but a good idea when possible),
(b) it obviously has more than one answer,
(c) the answers to the question have to be broad and far reaching, and
(d) the answers will result in a goal which is suggested by the issue.

What are some of the problems in formulating issues?

In some instances new issues will be formulated. A common error in developing issues is to ask a question that only has a "yes" or "no" answer. "Should the Bureau of Education for the Handicapped regulate the placement of children in special education program?" is not a good issue, because it can only be answered by "yes" or "no." That could be restated as: "Given that many children are misplaced in special education classrooms, what mechanisms can be instituted which will assure appropriate placement of each handicapped child in a special education program?"

Likewise, an issue is not good if it is too specific or narrow. A bad example: "What activities can the Handicapped Children's Early Education Program of the Bureau of Education for the Handicapped initiate that will promote further spread of curriculum for Early Education programs"? This asks a question that has definite limits, legislative and fiscal limits, only addresses one agency, and only works with a selected small target group. It would be better if the issue were phrased as: "Since the number of pre-school handicapped children served is significantly small, what actions or policies can be taken which will stimulate the growth of early intervention programs for this population?" You can see that the "good" issue will certainly provoke more innovative answers, with broader implications, than the "bad" issue.

All of these good issues also suggest goals and objectives, appropriate placement of greater numbers of children, and growth of early intervention programs. Practice formulating issues. Give yourself a problem, and then formulate an issue. You will soon find that issue making is not easy--but necessary--before you are through with your task.

But what about recommendations? The important thing to remember about recommendations is that they should, absolutely, irrevocably, and ineradicably, SUGGEST A PLAN OF ACTION IN CLEAR TERMS.

The reporting form asks States the level of agency that your recommendation will affect: Federal, state, local or private. Interpret this as the level(s) of agencies that will MOST IMMEDIATELY be affected by your recommendation. If your recommendation for stimulating growth of early childhood programs is one of intensive research at the university level, mark "private." If the recommendation is for a national information campaign, mark "federal." Or if more than one level is suggested, mark any or all that are appropriate.

The question about the disability(ies) affected is self-evident, and should need no explanation.

But then you are faced with formulating the recommendation. How do you develop a solution? As clearly, definitively, detailed and succinctly as possible. The easiest and best way to write a recommendation is to follow the reporters' code--Who, What, Why and How:

* Who should implement action toward the goal?
* What actions should be taken to reach this goal? (notice the plural of the word action)
* Why is this action superior to others and why should it be done this way? Sometimes this statement comes first.
* How should these actions be started, and by what time schedule?

As an example, assume you want to recommend that a public media campaign be used to stimulate growth of early childhood programs. You will develop a broad statement of your recommendation as the "Solution." Specific action steps to be taken would be presented as the implementation plan.

Solution: Growth of early intervention programs for handicapped children appears to be limited by general lack of knowledge about the benefits, as well as the methods of such procedures. Therefore, it is recommended that a wide-scale media campaign be mounted which will impart the information on human and cost benefits of early intervention projects to all taxpayers and attempt to influence their support of further growth. Such a campaign should depict successful projects of early childhood intervention and demonstrate the increased ability of handicapped children to cope as a result of early intervention.

Implementation Plan: The Bureau of Education for the Handicapped, through funds earmarked for Early Childhood Intervention Programs for the Handicapped, should award a contract for a public media campaign to impart information about the benefits and methods of establishing pre-school early intervention programs. Although such a program could involve state and local education information dissemination agencies, it is felt that a national effort is necessary to insure the rapid growth of programs and to reach more persons who will eventually have to decide on fiscal support.

Since funds already exist for activities like this in the Bureau of Education for the Handicapped, it is recommended that a contract for this work be awarded by January 1978 and that the campaign be mounted before the end of the 1977-78 school year. Such a campaign should utilize both print and nonprint media, with heavy saturation.

At the end of 1978, all state school systems and identifiable private service systems should be surveyed to ascertain growth of numbers of pre-school intervention programs.

That is a recommendation, broken into a "solution" and an "implementation plan." It is succinct, it gives a rationale, it answers the goal question of the issue, it locates the catalytic agency, it gives time schedules, it provides an evaluation of itself, and it suggests contents.

The importance of your role as a State delegate, in assuring that meaningful recommendations are developed as a result of the White House Conference, cannot be overemphasized. The success of the Conference depends upon you, the State delegate, and the degree to which you present meaningful solutions to the National Conference delegates for their consideration in May 1977.

WHITE HOUSE CONFERENCE TOPICS

HEALTH CONCERNS (HEC)

I. Research
II. Technology
III. Diagnosis
IV. Prevention
V. Treatment

SOCIAL CONCERNS (SOC)

I. Attitudes of the General Public Toward Handicapped Individuals

II. Psychological Adjustment of Handicapped Individuals and Their Families

III. Recreation

IV. Participation in Cultural Activities

V. Architectural Accessibility

VI. Transportation Accessibility

VII. Communications: Techniques, Systems, Devices

ECONOMIC CONCERNS (ECC)

I. Employment
II. Economic Opportunity
III. Economic Security

EDUCATIONAL CONCERNS (EDC)

I. Preschool (0-5 years)
II. School Age (5-21 years)
III. Post School (21 years plus)

SPECIAL CONCERNS (SPC)

I. Problems of the Severe Multiple Handicapped

II. Community and Residential Based Housing

III. Service Delivery Systems

IV. Civil Rights of the Handicapped

V. Unique Problems of Handicapped Minorities

VI. Unique Problems of Disabled Veterans

VII. Unique Problems of the Handicapped Aging

SUMMARIES OF AWARENESS PAPERS AND ISSUES

These Summaries were prepared by subject-matter experts to serve as one resource for discussions leading to solutions of problems facing all individuals with mental and physical handicaps. The Issues were prepared by the White House Conference, with input from consumers, organizations, other technical experts and the National Planning and Advisory Council. The Summaries and Issues were not intended to be all-inclusive, but were designed to stimulate discussion.

The White House Conference on Handicapped Individuals acknowledges, with deep appreciation, the production support from the Naval Ship Engineering Center, U. S. Navy

SPECIAL CONCERNS

Summary and Issues on

PROBLEMS OF THE SEVERE AND MULTIPLE HANDICAPPED

Awareness Paper Prepared By

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I. PROBLEMS OF THE SEVERE AND MULTIPLE HANDICAPPED

SUMMARY OF AWARENESS PAPER

Introduction

Over 10,000,000 of our citizens are confronted daily by problems of the greatest magnitude seldom faced by the rest of our society. They are our people who have severe or multiple handicaps. In many instances, they are confined to their apartments, homes or other residences because the architectural design bars leaving and entering. If they can leave their homes, more often than not, they are prisoners of their neighborhoods, because the public transportation system, accessible to all others, is inaccessible to them. They are discriminated against by employers, so they seldom earn wages with which to maintain themselves and their families in dignity and in decency. Public health, welfare and social service programs lack the elements and/or funding that would enable these 10,000,000 people with severe handicaps to achieve maximum functional capacity leading to independence of others in self-care, in travel and in coping with the other aspects of normal living. And, finally, social attitudes towards disability and towards them as "the handicapped" generally exclude them from participating in community, cultural and recreational activities essential to a full and complete life.

How to overcome, how to change these conditions are the concerns of our citizens with severe or multiple handicaps, and should be the concerns of our entire society.

The Severely and Multiply Disabled

There is no one universally accepted definition of "severe disability," nor is there consensus as to the basis upon which to develop such a definition. Some people equate "severe disability" with certain body impairments, others with inability to perform various tasks or engage in specific activities. To compound matters, each of our public and voluntary health, education, rehabilitation and social programs has its own definition related to its objectives and best suited to its operations.

The Rehabilitation Act defines "severe handicaps" for vocational rehabilitation purposes as a:

> "disability which requires multiple services over an extended period of time and results from amputation, blindness, cancer, cerebral palsy, cystic fibrosis, deafness, heart

disease, hemiplegia, mental retardation, mental illness, multiple schlerosis, muscular dystrophy, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia and other spinal cord conditions, renal failure, respiratory or pulmonary dysfunction, and any other disability specified by the Secretary in regulations he shall prescribe."

The Social Security Act (Title II, Disability Insurance and Title XVI, Supplementary Security Income) defines a disabled person as one who is

> "unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months .... or is blind."

The Office of Handicapped Individuals (of the Department of Health, Education and Welfare) established by Title IV of the Rehabilitation Act with resonsibility for examining what is currently being done and planned for handicapped individuals throughout the Federal government developed and applies the following defintion:

> "A handicapped individual is one who has a physical or mental impairment or condition which places him at a disadvantage in a major life activity such as ambulation, communication, self-care, socialization, vocational training, employment, transportation, adapting to housing, etc. The physical or mental impairment of condition must be static, of long duration, or slowly progressive."

This definition excludes conditions of the get-sick-get-well variety. It also excludes conditions which have little or no impact on the individual. It is felt that the very broad definition is necessary for planning purposes. It is intended to provide an umbrella under which all programs with more narrow focus and very particular definitions can be accommodated.

Thus it can be seen that many factors enter into the identification of people as "disabled", "severely disabled", and "multiply disabled". Among these factors are body impairments, the functional limitations resulting from the impairments, the environment, education, age, community and employer attitudes and, equally if not of greater importance, the self image of the person with the impairment. People differ in their capacities to cope with impairments, and therefore, even between people with identical conditions, the severity of the disability may vary. Moreover, many persons who are blind, deaf, retarded and using wheelchairs object to the stereo-typing of all such persons as "severely disabled".

Estimates of Severely Disabled Population

In authorizing the President to call a White House Conference on Handicapped Individuals, the Congress found, among other things, that "there are seven million children and at least twenty-eight million adults with mental or physical handicaps".

Estimates of the number of disabled individuals in the United States vary, as the surveys from which the estimates are derived use differing definitions of disability and survey methods. As a consequence, there are no exact, hard data concerning the number of people who might make up the "disabled", the "severely disabled" and the "multiply disabled" population. There is great need for the development of a system that will identify the incidence and prevalence of severely handicapped individuals in the United States, as well as other information essential for planning programs to meet their needs.

The Urban Institute, in a recent study of individuals with the most severe handicaps asked various voluntary agencies to report the "most severely disabled" incidence and prevalence data for the population of concern to them. Using their responses and data from other studies, the Urban Institute estimated the number of individuals with the most severe handicaps in the United States in 1975 to be over 10,000,000 as follows:

Noninstitutional Population	8,280,000
Under age 18	180,000
18-64	4,200,000
65 and over	3,900,000
Institutional Population	1,787,000
Total U.S. population with most severe handicaps	10,067,000[1/]

The Urban Institute estimates that by 1984, the total number of severely disabled and moderately disabled individuals will increase

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1/ Report of the Comprehensive Needs Study of Individuals With the Most Severe Handicaps, submitted to the Department of Health, Education and Welfare, June 9, 1975. The Urban Institute.

to 38,648,000 of which almost 13,000 will be severely disabled.[2/]

Service Delivery Systems - Public Agencies

The government programs serving people who are handicapped are extensive and varied, designed to serve different purposes and relying on different definitions of the concept of disability. Some programs are dedicated exclusively to disabled people; others utilize program earmarks or components for the disabled. Some are limited to specific disability groups, while others are unrestricted in the disabled people they serve. Some focus on severely disabled people alone; others focus on all disabled people. They use varying methods in providing their services and the extent to which services are provided varies considerably among the programs.

Prior to 1973, there was no single Federal agency responsible for an overall review and comprehensive look at the Federal programs and policies affecting disabled people. The Rehabilitation Act of 1973 in recognition of this deficiency, created The Office for Handicapped Individuals within the Department of Health, Education and Welfare, responsible among other things for review, coordination, information and planning pertaining to the policies, programs, procedures and activities of the various programs for the physically and the mentally handicapped.

The Office for Handicapped Individuals surveyed all Federal programs which serve the handicapped. This study, concluded in March 1975, identified 75 programs whose primary mission is to serve the handicapped; 6 programs not exclusively for the handicapped, but which emphasize service to handicapped individuals; and 45 programs which serve handicapped people on the same basis as others. Nearly all of the programs identified as benefitting disabled people also benefit those people who are severely handicapped. Most of the services for the severely handicapped people are in the form of basic support (income maintenance), health and medical care, social services, educational services and vocational rehabilitation. By far, the greatest expenditures are for income maintenance and health and medical care. Payments for educational services, vocational rehabilitation and other related and direct services are minimal in comparison.

2/ Working Paper 0981-02 Modeling and Forecasting Disability Information, submitted to the Department of Health, Education and Welfare, June 9, 1975. The Urban Institute.

The Disability Insurance, the Supplemental Security Income and the Aid to Families with Dependent Children programs under the Social Security Act are the major income maintenance programs for individuals who are severely disabled. With prolonged severe disability, the finacial resources of the individual so affected and his family are soon exhausted. Thus, people with severe handicaps have fewer resources than persons without such handicaps and generally are completely dependent upon payments from income maintenance systems for their survival. Often these payments are insufficient to meet basic needs. Moreover, the income maintenance programs contain provisions that serve as disincentives to employment.

Maintenance of health in general for those who are severely disabled involves attention to both conditions which require hospitalization as well as minor medical problems. These ongoing health problems may be related to the person's disability or the problems may be common to all individuals, such as infections, malfunction of certain internal processes, dental problems, etc. The high cost of medical care is felt by most Americans, but to a person severely disabled, it can especially limit access to such care.

A basic need of many disabled people is to remove economic dependency upon others or upon income maintenance programs through services which help the disabled person achieve gainful employment or self-support. The primary government program which delivers these services is the Vocational Rehabilitation Program. Services under this program include: physical and mental restorative services, such as medical and corrective surgical treatment, hospitalization, prosthetic, orthotic, and other assistive devices, and physical and occupational therapy; psychological services; training, including personal and work adjustment; maintenance; transportation; reader services and orientation and mobility services for the blind; interpreter services for the deaf; and post-employment services.

During Fiscal Year 1975, State vocational rehabilitation agencies rehabilitated 324,039 persons of which 115,746 persons were deemed severely disabled.1/ Until more precise statistical data are available, it is not possible to state with any degree of

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1/ Annual Report for FY 1975. Rehabilitation Services Administration, Department of Health, Education and Welfare.

accuracy how many of the 10,000 people with severe disabilities could benefit from and need vocational rehabilitation services in order to return to work or to engage in work for the first time. However, it is reasonable to assume that the number of such people far exceeded the approximately 116,000 rehabilitated into employment by the Vocational Rehabilitation agencies in 1975. But the state vocational rehabilitation agencies and the facilities which they utilize for services will not be able to reach and serve increased numbers of severely disabled people unless the funds for rehabilitation purposes are vastly increased. In addition, funding for research, demonstration and training must also increase if the national rehabilitation effort is to be responsive to the needs of the people who are severely disabled. In a recent study, the Urban Institute estimated that of the $21.5 billion that was spent to assist the 10-11 million severely disabled people in 1973, less than $ 4 billion or about 2% of the total budget was spent for vocational rehabilitation services to this group.2/

A major concern of consumers and providers with respect to the vocational rehabilitation system is what is commonly called the "numbers game". Potential consumers of VR services who have severe disabilities, and who are frequently ignored because the counselor is busy with "easy rehabs", have been quite critical of the "creaming" (or selecting of the easiest applicants) that takes place. Even with the Rehabilitation Act of 1973's priority on the severely handicapped, many counselors in the field still feel pressure for quantity rather than quality.

In the Comprehensive Needs Study's survey of rehabilitation providers the problem of rehabilitation closures was seen as a major impediment to serving individuals with severe handicaps. The fact that the VR agency is "required to rehabilitate the maximum number of disabled to retain its appropriation and support" is, in great part, what leads to the "inappropriateness of rehabilitation quotas (stated and implied) imposed upon VR counselors." To correct these major impediments, a policy option is the implementation of a weighted case closure system in VR to provide greater incentive for working with the severely handicapped.

2/ Report of the Comprehensive Services Needs Study. The Urban Institute.

Service Delivery Systems - Private Agencies

In the United States, there are hundreds of private agencies, associations, fraternal and religious societies, veterans' groups and self-help and consumer organizations, all having a full or partial purpose of serving the needs of people who are handicapped. Membership in these organizations totals in the hundreds of thousands. Most are national organizations with state or local affiliates; some are purely community organizations; and a few are international in scope.

Many of these private associations initiated the earliest programs in continuous service, some established as early as the nineteenth century.

In recent years persons with disabilities have begun to organize themselves as an effective minority seeking their full civil and human rights. National organizations of the blind and of the deaf have been strong advocates for years. In the past two decades, the Paralyzed Veterans of America, The National Paraplegia Foundation, Disabled in Action and others have emerged as organizations of, by and for the physically handicapped. State coalitions have developed that cut across as many as 40 disability groups. Within the past two years, many of the national consumer organizations and state coalitions have joined together to cooperatively solve problems common to all citizens with disabilities. Under the umbrella of the American Coalition of Citizens with Disabilities, their stated purpose is "to promote the social and economic well-being and to assure the full exercise of human and constitutional rights of citizens with disabilities."

The thousands of private organizations and facilities concerned with disabled people provide a vast array of services. They conduct research leading to improved health and rehabilitation practices and techniques. They conduct and promote public and professional education programs on the causes, treatment and prevention of various disabling diseases. They seek to meet the special needs of certain disabled people, such as providing braille publications for people who are blind or teletypewriters for people who are deaf. They attempt to serve as advocates for disabled people in promoting the legislation and other action that is required to remove employment barriers, architectural and transportation barriers and the attitudinal barriers that prevent disabled people, in particularly those who are severely handicapped, from leading full, productive lives. And, principally through the more than four thousand rehabilitation centers and workshops,

they provide the restorative and rehabilitation services which disabled people often require to attain their full functional capacity.

Often the private voluntary agencies including consumer organizations receive public support for some phases of their activities. Continuing public support is essential to the survival of these voluntary agencies and to the continuation of the unique activities which only they can carry out. With inflation and unemployment, private support of many voluntary agencies is diminishing. A critical issue, therefore, is continuation of public support to these private agencies in amounts which take cognizance of increased costs due to inflation and to diminishing voluntary support due to inflation and unemployment.

Evaluation of Service Delivery Systems

Assessing the consistency of services from area to area, the gaps in services from program to program or the evaluation of services from individual to individual is a difficult task. So many different factors (on which very little hard data exist) can influence such assessments. One possibility for significant program evaluation that is recently receiving considerable attention is that of consumer evaluation of services.

Attitudinal and Physical Barriers

Individuals with severe handicaps are confronted by attitudinal, transporation, architectural and other barriers which have a vital affect upon their livelihood, their well-being and their roles in society.

Indifference which is related to unawareness, uncertainty and apathy accounts for the lack of concern by the general public, communities and institutions about the continuation of the many man-made barriers that prevent severely handicapped people from achieving and enjoying the quality of life available to others in our society. As long as this indifference continues, severely handicapped people will be discriminated against in renting apartments, in securing employment, in securing credit and in having equal access to all aspects of our society.

Correction of that indifference is basic to the removal of architectural barriers that prevent disabled people in wheelchairs and others from using public buildings, from entering places of employment, from using banks, department stores, restaurants,

recreational centers and even from entering and leaving their apartments and homes. Correction of this indifference is also essential if the public transportation systems - buses, trains, planes, subway cars, which now are inaccessible to severely handicapped people are to be made accessible to them.

Rehabilitation agencies, public and private, consumer organizations and other state, county and municipal organizations need to take strong advocacy roles for adequate legislation and other action to bring about barrier-free buildings and facilities, including housing. In addition, it would be of help to many severely disabled individuals to have a local program giving information on how modifications could be made and on types of devices which assist in performing various household functions. Such a program could include assistance in finding barrier-free housing. Since the bulk of the costs of architectural modifications is now absorbed by individuals or families, many in the low income brackets, some sort of financial assistance should also be considered.

On the broader level, greater enforcement of existing standards for a barrier-free environment would do much to assist the most severely handicapped. Without accessible homes, offices, public buildings and areas, the probability of the severely handicapped achieving the better quality of life envisioned in the act establishing the White House Conference on Handicapped Individuals will be low.

Goals of Rehabilitation

Rehabilitation has the objective of providing services for the disabled individual that will help each such person achieve the fullest potentialities for whatever satisfactions that person wants in life, and is able to attain. By providing help toward recovery of function and restoration of capacity, it is an important means for increasing independence, dignity, and self-respect. At one end, the maximum attainable goal may be progress from bed to wheelchair or an increased capacity for self-care. At the other extreme, it may be aimed at restoration to paid employment. The former is often designated as "rehabilitation for independent living"; the latter is designated as "vocational rehabilitation".

Among the 10,000,000 severely disabled individuals in the United States today, most are dependent on others for their support or for assistance in activities of daily living. If they were provided modern rehabilitation services, millions could live their

lives in independence and with greater dignity. Many of these could return to work, or work for the first time. Others could learn self-care. In either case, the benefits from rehabilitation services would extend not only to the disabled persons alone, but to their families and to siciety as a whole. For those who return to work, lost wages would be restored, industry would regain labor skills, and there would be new purchasing power and tax revenues in the economy. For those who were freed from constant attendance or dependency, institutional, disability income and welfare costs would often be decreased.

Rehabilitation for Self Care

It is not possible to estimate with any exactitude the number of severely disabled people who could benefit from rehabilitation services which would enable them to meet, without assistance, the normal demands of daily living - dressing themselves, feeding themselves, taking care of their other personal needs - participating in family and community activities. It is reasonable to assume that they number in the millions. They are among the two million Americans who are homebound - the two million people who are "so limited by reason of the severity of their physical, emotional, intellectual and environmental disabilities that they cannot regularly leave their homes with the transportation normally available to them to participate in community-based employment, social and educational activities."1/ They are among the four million people with severe disabilities who are 65 years of age and over, many of whom are in nursing homes. And they are among the almost two million of all ages who are in institutions. Very substantial numbers of these people could achieve either full or a greater degree of independence in meeting their daily living needs and in engaging in community and social activities if they were given the opportunity to receive rehabilitation services.

There is no single nation-wide State-Federal program which provides rehabilitation services to severely disabled people to enable them to achieve independence in meeting the normal demands of daily living. Such rehabilitation services that are provided for this purpose are provided, as a rule, through rehabilitation centers. Sometimes they are included in institutional programs; sometimes they will be found in hospital programs; sometimes they

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1/ Homebound Rehabilitation: Preparing the Way, Journal of Rehabilitation September/October, 1975.

will be found in homes for the aged or nursing homes. Occasionally, there are community programs which bring these services to the disabled individual in his home. Most often the absence of such rehabilitation programs and services in our communities is the rule rather than the exception.

A critical issue is how to establish programs throughout the country that will assure the provision of rehabilitation services for independent living purposes to the millions of severely disabled people who could benefit from such services.

Vocational Objectives

It has been demonstrated in thousands of individual instances that severely disabled people, regardless of the severity of their disabilities, can compete with their able-bodied peers in all of the professions, in industry, in commerce, in government - in fact in every work situation in our society. And yet, they are unemployed in far larger numbers proportionately than non-handicapped people. Where a certain occupation might be considered as suitable entry jobs for a young able-bodied person starting a working career, these are often top career jobs for people who are severely disabled. While vast amounts of money - in the thousands of millions of dollars-are spent on professional, vocational and other career training, severely disabled people benefit very little because the facilities are inaccessible, transportation unavailable and the few modifications required to accommodate their conditions are lacking.

Millions of severely disabled people could compete on equal basis with their able-bodied peers for positions in the competitive labor market if they could obtain the rehabilitation services which they need through programs designed to reach them in their homes, in institutions, or which otherwise made the rehabilitation services readily accessible and available. The models for such programs are well known and their validity established. For example, through one such model people severely disabled and confined to their homes (by rheumatoid arthritis, muscular dystrophy, cerebral palsy, multiple sclerosis, rheumatic heart disease, paraplegia and quadriplegia from spinal cord injuries) are earning substantial wages, many outside their homes, in the information industry as computer programmers, microfilmers, data entry operators, inspectors and in other related occupations and skills. The techniques for establishing severely disabled people in these and in hundreds of other occupations in competitive industry are known. What is lacking and urgently needed are the resources with which to establish these special programs in all communities

throughout the nation. What is also needed is vigorous enforcement of existing anti-discrimination legislation, particularly Sections 501, 503 and 504 of the Rehabilitation Act of 1973, as amended which pertain, respectively, to employment of handicapped individuals in government, employment of handicapped individuals by employers under Federal contracts and to the prohibition of discrimination against handicapped people in any program or activity receiving Federal financial assistance.

There are some severely disabled people for whom placement in competitive industry is not feasible. These people need and can function well in sheltered work situations. For example, there are 30,000 to 40,000 blind persons in the United States who could benefit from sheltered workshop services.1/ Many of these people in addition to being blind have been further disabled by cerebrovascular and cardiovascular accidents, cerebral palsy, mental retardation, mental or emotional illness, deafness or severe hearing loss, diabetes, orthopedic disorders including amputations; tuberculosis, alcoholism, drug addiction, and other disorders. Only about 5,000 such blind individuals are currently receiving the rehabilitation and employment services which the sheltered workshops have to offer, and these blind people are principally in the 87 workshops (in 36 states) affiliated with the National Industries for the Blind. Workshops for the blind, like those for other disabled people, have been supported over the years through voluntary contributions and philanthropic requests. They have been strained to their financial limits and cannot, without direct public support, meet current needs. Sheltered employment both in special workshops and in competitive areas needs to be developed for many individuals who are mentally retarded. It is estimated that there are at least 400,000 retarded persons living in the community who have the potential to work, but who are now unemployed. There are other individuals with single or multiple severe disabilities who need work under sheltered conditions - an amputee with a heart condition for example.

Many severely handicapped persons currently employed part-time or unemployed, could be employed in the competitive economy if sheltered work tailored to their capacities were developed in the competitive work environment. The few demonstrations that have been developed suggest that assisting an employer in designing the appropriate work environment is potentially very effective.

1/ Harold Richterman, Services to the Blind: A Community Concern, Eleventh Institute on Rehabilitation Services. (DHEW).

Under such a program, the employer would be paid by the government the difference between the value of the worker's product and the minimum wage or pay a fixed percentage for certain kinds of employed severely handicapped people.

In order for sheltered workshops to pay a minimum wage to workshop employees, government wage supplements would be necessary for eligible employees. In addition, consideration would need to be given to legislation and support providing for unemployment compensation, Social Security, and health insurance coverage for all employees in all sheltered workshops, as well as inclusion of workshops within the National Labor Relations Act. Also, there is need to consider amending the Social Security Act so that Disablity Insurance and Supplemental Security Income payments are not affected by earnings in sheltered workshops or in competitive employment until earnings exceed a level that provides an incentive for rehabilitation. Of equal importance is continuation of health coverage under Medicare or Medicaid for the beneficiary who is rehabilitated until such time as adequate health coverage under another program is provided.

Should a public works program be established to cope with the current unemployment situation, adequate provision should be made to assure that disabled people, including the severely disabled, are employed. A public works program could also provide employment for able-bodied persons as readers, interpreters, and attendants, thus increasing the support personnel needed to facilitate independent living.

ISSUES

SPC I-1 What are the unique service delivery problems of the severely handicapped and how can they be accommodated?

SPC I-2 How can the needs of the severely handicapped be protected through advocacy?

SPC I-3 How can decision makers be convinced to expend more private/public funds for the treatment and rehabilitation of the severely handicapped?

SPC I-4 What programs can be established to enable the severely handicapped to improve their ability to live independently or function within their families and communities?

SPC I-5 How can we meet the attendent care requirements of the severely handicapped?

SPC I-6 How do we build and adequate public/private financial base at the federal, state, and local levels to meet the needs of severely handicapped people?

SPC I-7 How can the severely handicapped develop an effective lobbying constituency?

SPC I-8 What changes should occur in the Social Security Disability Insurance and Supplemental Security Income Laws to exempt earnings to a point which would serve as an incentive to the severely disabled to undergo rehabilitation and to work?

SPECIAL CONCERNS

Summary and Issues on

COMMUNITY AND RESIDENTIAL BASED HOUSING

Awareness Paper Prepared By

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II. COMMUNITY AND RESIDENTIAL BASED HOUSING

SUMMARY OF AWARENESS PAPER

Historically, persons who lived with paralysis, retardation, mental illness, deformity, or disease found help from those who loved them, or they struggled on their own. Their needs had to be met in their immediate community of friends or through tremendous personal will to survive. Often the attitudes of society precluded any but peripheral participation in the mainstream activities of life. Handicapped persons were perceived as deviants, and thus expected to feel and act differently than other persons. As a result, they were placed in institutions, and ghettos of societal outcasts were created as an excuse for dealing with special housing or socioenvironmental needs.

Today many people survive and overcome great mishaps and trauma, but archaic attitudes continue to prevail over their lives. Many disabled people are confined to institutions where they are treated as objects or patients rather than individual human beings. They are frequently grouped by disability type with insufficient regard for special needs or functional abilities. Despite movements for increased personal rights and equal protection for many minorities, and despite an awakening awareness by the public about the realities of disability and the dehumanizing effects of institutions; repressive management, prejudicial practices, and substandard facilities continue to exist in and function as institutions.

Many other disabled persons are confined to their homes and isolated by the fact that they cannot use public transportation, or telephones, or bathrooms, or drinking fountains, or steps, or sidewalks, and so forth. Many unique services and accommodations are needed by handicapped individuals according to their disability, and if these persons are to lead a normalized life, these services and accommodations must be available throughout their community.

One must look at housing from a holistic perspective in order to recognize the need for a comprehensive systematic approach to the problems. Because every individual has different needs, there must be a variety of living arrangements in different locations available to choose from.

Few people realize the extent of the problems which face every handicapped individual who is in need of housing in the United States today. At the community level there are service voids. Disabled persons who can manage by themselves in apartments or houses, or those who consider boarding or convalescent settings sufficiently independent to meet their needs are restricted in their choices and activities and often relegated to a small niche. The environment discourages mobility and needed services are confined to specific institutional settings.

Further disincentives to independent living are caused by zoning laws, licensing rules, restrictive standards, income limits, population parameters, exhorbitant insurance costs, fire laws, subsidy qualification requirements, and so on. Some of the problems result from a demographic void. No one knows how many disabled people are in what kind of housing and at what kinds of disadvantages.

Perhaps the greatest difficulty in providing satisfactory housing for persons with disabilities is the lack of coordinated legislation and effort. There is a need to improve the methods of implementation. There are many programs and laws in the United States today designed to protect and assist handicapped individuals in need of housing. However, due to the fact that legislation has not been implemented to provide comprehensive planning and delivery of services, these programs have been fragmented and the laws have in general been ineffective.

Costs are sometimes given as an excuse for not providing needed services or developing alternative housing models so that a continuum of living arrangements is available. It is apparent, however, that a systematic approach which accommodates individual lifestyles may be more cost-effective than the traditional categorical approach.

In spite of all the problems, obstacles, disincentives, and gaps, noteable progress on housing disabled persons in the community is being made. Several community based alternatives to nursing homes and institutional housing arrangements have been tried. Some communities have even begun to develop systematic programs. Foster homes, boarding homes, cooperative or sheltered apartment programs, lodges, domiciliary programs, and halfway house programs are becoming more and more common. Also, more handicapped persons are able to live independently as public services and facilities begin to accommodate persons with special needs.

There is a great deal of development and research which must occur before any valid comparisons or unqualified judgements can be made about the quality of life stimulated by these environments. Even so, experience has identified many new directions which must be followed to reach the ultimate goal of a freely chosen living arrangement suitable to the needs of every American, without regard to disability.

ISSUES

SPC II-1 How do we discover current needs and preferences and project future needs in the housing market for handicapped people?

SPC II-2 What should be the role and the responsibility of public and private agencies, the community, the consumer, in determining housing needs?

SPC II-3 What should be the role and function of government (federal, state and local levels) in provision of community living programs?

SPC II-4 What federal, state, local agencies should provide housing subsidies and who should be eligible for these subsidies?

SPC II-5 What support services need to be incorporated in housing assistance plans to accommodate all varying disabilities?

SPC II-6 Under what circumstances should handicapped individuals be segregated and/or integrated in public and/or private housing?

SPC II-7 What are the needed standards and design concepts for various kinds of housing facilities for the disabled?

SPC II-8 Who should be involved in the establishment and implementation of standards and design concepts?

SPC II-9 How can currently available housing be made more suitable for housing handicapped individuals?

SPC II-10 How can inter-departmental program policies and services be effectively coordinated to facilitate independent living?

SPC II-11 What are some approaches to expanding living choices?

SPC II-12 What legislative action at federal, state, local levels stimulate and provide community-based housing?

SPC II-13 How do we enforce the Civil Rights of handicapped persons as they relate to housing and what should public policy state about the rights of handicapped persons who require specialized housing?

SPECIAL CONCERNS

Summary and Issues on

SERVICE DELIVERY

Awareness Paper Prepared By

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III. SERVICE DELIVERY SYSTEMS

SUMMARY OF AWARENESS PAPER

BACKGROUND

Introduction:

For nearly 200 years this country has been attempting to devise an effective program of services for handicapped individuals in the communities of America. However, it has only been since 1950 that significant strides in the direction of comprehensive services have been taken. It has only been during the last decade that notable achievements have been reached.

Part of the progress has been made because national attention has been drawn to the nearly 25 million persons in our society who have special needs due to some handicapping condition. Much of the gain has been a result of expanded research in the area of human development and rehabilition. A large amount of the success is due to comprehensive approaches to health, social and educational problems and issues from the national level. Major generic programs such as social security, the poverty program, economic development, comprehensive health and insurance, and programs designed to improve the quality of life all help identify and reduce the incidence and impact of handicap on the person and society.

Special federal and state legislation, and consequent service program development, from the time of the Kennedy Administration to the present day; notably the Comprehensive Mental Health-Mental Retardation laws, the Veterans Administration laws, the Economic Opportunity Act, the Rehabilitation Act, the Civil Rights Act, the Maternal and Child Health laws, the facilities construction laws, and the Developmental Disabilities Act, have created a fabric of activity, yet uncoordinated which sets the stage for effective action. There is still substantial progress to be made, especially in the area of the integration of human services at the local level, but the momentum of the '60s and '70s make 1980 goals and objectives statements more attainable. The key will be the extent to which consumer, provider, professional and bureaucratic structures can develop and implement effective plans and accountable systems of service and evaluation activity.

The author wishes to acknowledge the contribution and close cooperation of Dr. Ronald Wiegerink in the development of this paper.

STATUS

In every field there are critical dimensions and issues which must be identified in order to develop conceptual and definitional parameters for the problems. A review of current issues in the field of services to handicapped persons would include the following points:

1. Generic services versus specialized services.

2. National versus local delivery systems.

3. Consumer-provider salience in planning and service delivery systems.

4. Cost/social benefit.

5. Evaluation and planning.

6. Cross-categorical versus the categorical maintenance of services for handicapped individuals.

7. Manpower and quality control.

8. Research application.

9. Resource development.

10. Public awareness/education.

11. Legal advocacy/legislation/follow-through.

12. The integration of human service systems.

NEEDS-RECOMMENDATIONS

A review of current issues and a perusal of current service delivery systems reveals some factors which need to be addressed immediately and over the next few years.

1. The integration of human service systems

   There has been an ever expanding rhetoric on this topic over the last few years. General statements of problems and goals constitute the bulk of the statements coming from all levels, both public and private. Essentially, the discussions and presentations of the "integration of services" and the need for an improved method of integration and coordination amount to a body of general belief or prevailing philosophy that is commonly

held by professionals and the special interest groups which comprise the constituencies of this effort, especially in the area of handicapped individuals. In a report by Gage (Integration of Human Services Delivery Systems) it is stated that the federal Department of Health, Education and Welfare regards the impact of HEW services as less than the sum of its program parts. This is said to be due to -

a) service programs are not correlated with a common set of national goals and service objectives.

b) they are not responsive to the multiple needs of the clients that they serve.

c) they are not orchestrated through centralized, comprehensive planning processes of state and local levels.

d) they tend to be narrowly prescribed and rigidly regulated.

e) they not only fail to complement one another, they typically do not mesh with other federal programs inside or outside of HEW.

The problem of integrating service programs includes a variety of subfactors. The political values of remaining unique helps maintain a competitiveness between agencies and specialized service programs that works against the integration of human service programs at all levels.

The difficulty of developing a common or shared information data base slows down the movement toward attempts to develop better integrated service systems.

The development and implementation of services along disciplinary lines tend to hold up cross-agency or trans-agency programming just as there is a continued resistance to cross-disciplinary or trans-disciplinary training and manpower development.

At the current time there is a slow but steady trend toward human services or human resources agencies at the local (county) level which would help blend the health, mental health, rehabilitation, social services and other programs rather than to maintain the current, separate generic agencies. At the top (the federal level) there

is an attempt to blend together health, education and welfare or social services programs within the Department of Health, Education and Welfare. This situation might well be inverted to the point where a separate, cabinet level, federal agency would be established for health, for education, and for social services that would provide coordinated planning and the development of criteria, policy, regulations and monitoring activities to an increasingly integrated system of state and local agencies. In other words, the current situation where the local agencies are separate and poorly coordinated and the national agencies are attempting to come into a more blended configuration should be inverted to separate out federal agencies into special cabinet level programs while the local programs are becoming more blended or integrated. This would allow for a shift away from direct service delivery by federal and state agencies toward a program development, resouce development, technical assistance, monitoring and evaluation role and place the local (county and municipal) agencies into a more effective, integrated service delivery pattern.

2. Meshing of planning, service, research and training -

The flow of information and activity through the sequence of planning, program development, program implementation, research and development, evaluation and training is poorly carried out at the present time at all levels. There is a need to orchestrate the planning, resource development, and program development activities of services and training programs, including higher education as well as field-based training and education programs, and further to articulate planning and program development activities with research and development and dissemination programs which are increasingly remote from the service systems as well as the training programs designed to staff the service systems.

A regional policy, planning, service, training and program development mechanism should be put in place that would provide for the unique service program responses that arise from the special local, state and regional service needs of handicapped individuals. This regional meshing activity would bring together the necessary information, planning, service, training and research and development programs and would result in a more effective articulation and delivery of services than is now available.

3. Improved match of consumer-client input with agency-organizational input in the development and delivery of service programs -

While consumerism has increased at a dramatic rate since the middle 1960s, the Developmental Disabilities Act is the only major piece of federal legislation that is being implemented now at the state and local level that institutionalizes or requires consumer involvement and input in the planning, program development and service delivery activity for handicapped individuals.

The involvement of consumers, especially the handicapped, is an absolute necessity to improve the quality and propriety of the service that is needed as well as to guarantee that an appropriate and objective evaluation can be derived as a result of mounting service program costs.

A center for the development and study of consumer involvement in human services programs should be established to complement the federal, state and regional organizations now in place.

4. It is necessary to install a monitoring, evaluation and feedback activity into the planning process -

At the moment, information developed for planning, service, training or research programs in the area of the handicapped is not sufficiently accurate or fresh to assure timely and effective service delivery systems. Monitoring the effectiveness of programs, evaluating programs and providing feedback to the planning and program development activity from the monitoring and evaluation activities is poorly accomplished. In addition, there is an urgent need for the development of cost-benefit studies, particularly research into the appropriate measures of input and output of human services programs that would allow for more effective evaluation. Cost-benefit studies thus far have not yielded useful units of measurement or sufficiently useful measurement or methodological approaches that would provide for the type of program evaluation and cost-benefit statements that are available to other fields such as industry and agriculture.

A special effort should be mounted to focus the issue of measurement, methodology, and systems for monitoring, evaluating, improving planning and developing cost-benefit strategies for programs in the area of handicapped individuals.

5. A review of the merits of public education -

Millions of dollars have been poured into propaganda, public awareness and public education programs in the mental health, special education, rehabilitation, health, of the nature of handicapping conditions, or a positive change in the attitudes of the general public toward the handicapped and the positive contributions that the handicapped population is making in our society. Further, the mobilization of public interest and public support for service, training and research and development activities in the area of the handicapped has not been as effectively accomplished as is necessary in order to mount the public support, attention and resources necessary in the years ahead to prevent handicapping conditions and to provide for the special service needs of those who are handicapped in our communities.

A special effort must be undertaken to study the variety of strategies which have been used effectively to mobilize public support for other issues. In addition, new approaches to public education and the strengthening of our effort to increase public awareness in the area of the handicapped must be undertaken, particularly among lower socio-economic groups. Without a background of moral and financial support for the variety of programs needed to serve handicapped individuals, no further progress can be made and recent gains will be lost.

6. Closer coordination of governmental branches -

The route of the special interest groups (notably parents) toward developing service programs for handicapped children and adults has moved from pressures on legislators and congressmen for specific legislation, to pressures on the executive branch of state and federal government for more enlightened leadership, to a legal advocacy which maximizes utilization of the judicial branch on behalf of handicapped individuals (notably class action litigation).

There needs to be a more effective, non-partisan coordination between legislative, executive and judicial branches with regard to leadership, legislative development, and judicial support in order to aid in the development of a more integrated and effective network of human services programs for handicapped individuals.

A mechanism should be established to assist states toward a better orchestration of legal and legislative activity with executive and agency implementation which "fits" with the judicial and legal interpretation and enforcement activities within states.

In short, what we may not need is further litigation. What we do need are successful demonstrations of how current consent decrees can be fulfilled.

7. The provision of adequate financial stability directly to handicapped individuals is sorely needed -

Social security, insurance benefits (both public and private), stipends, tax relief, job training, job provision and other individual support strategies must be expanded and increased for handicapped persons to the point where the matter of adequate income does not hamper the handicapped person otherwise coming to grips with the problems of community, family and personal adjustment.

A national program supported by state and local agencies and the general public must be initiated which will provide a guaranteed annual income and a variety of individual financial supports to handicapped persons to support and assure the personal welfare of each handicapped person in our society.

8. There has been a lag in the application of technology to the problem of handicapped persons -

A recent, belated effort on the part of the federal government to transfer some of the technological products developed during the active years of the space program (NASA) constitutes one of the few efforts to systematically review the current and developing technologies (hardware and software) which could be applied to alleviation of those conditions which handicap many of our citizens or to prevent or preclude the existence of those conditions which lead to handicap.

The utilization of visual communications technology for diagnostic activities in rural areas, the utilization of new types of materials for prosthetic devices for the physically handicapped, the use of computer-based instructional systems for mentally retarded children and other specific activities are but a few of the many opportunities that may lie in a systematic review of the full spectrum of

technological development experienced in this country over the last 30 years which might be of some immediate and long term value for handicapped persons.

Similarly, those special inventions developed for handicapped persons (deaf, blind, retarded) might be of great benefit to other special populations in our society.

9. There has been a continued focus on defect rather than on environmental determinants and the arrangement of the environment to prevent or to alleviate the effect of handicapping conditions -

The continued notion that a handicap is a defect results in persons being labeled and seen as deviant in the general society. This works against the best interests of the handicapped person and retards if not precludes advances in the adequate understanding of handicapping conditions and the development of adequate service delivery systems to meet the needs of handicapped individuals.

Greater support should be given to developing and expanding the base of knowledge which has grown over the last few years which is essentially an ecological approach to the understanding and alleviation of the effect of handicapping conditions, especially mental retardation. Environmental and socio-cultural determinants of handicap are poorly understood. Improved research, development and demonstration service programs need to be mounted in order to more fully explore this major source of handicapping conditions and handicapped persons and the extent to which environmental manipulation and cultural redefinition might be satisfactory remedial and preventive measures.

10. The role of higher education -

Higher education, particularly graduate schools and community colleges, are still inadequately involved in the training effort required to develop and implement a comprehensive and effective service delivery system for handicapped individuals throughout the country at the local level.

The traditional role of higher education as the knowledge generation organization must change significantly in the direction of a needs-related training strategy with joint planning with service programs. In this way, the data base necessary to plan and develop service programs can be

shared between the manpower development organizations and the service delivery systems with a consequent orchestration or synchronization between the two systems. The current situation where service programs are being planned and developed only to be stalled by the lack of adequate numbers and types of personnel is unnecessary and unforgivable even given the state of the art of our current planning and evaluation skills.

Higher education is, in most instances, available and willing to participate in the development of objectives, priorities and strategies for meeting the service needs of handicapped individuals. However, an extra effort must be made to help link the institutions of higher education with the service delivery systems, especially at the state level, in order to assure adequate joint planning and program development and the successful delivery of competent staff, on time, for the necessary service programs. This will require special block funding to universities for correlated work with block funded service agencies.

11. Continuing, back-up support systems for services -

Insufficient attention has been paid to the need for continuing technical assistance organizations, to provide for in-service training, staff development, consultation, resource development and the program assistance necessary on a continuing, back-up, support system basis for service programs. Demonstration programs, information dissemination, skill development, capacity building and technical assistance are a necessary part of any comprehensive service delivery system. Technical assistance is a process whereby new knowledge, materials, special skills and information about related service activities can be brought to even the smallest element of a comprehensive service network in a systematic way. Technical assistance organizations, typically limited to small state agency staffs, must be expanded to provide the kind of continuing support and assistance necessary to help mount a significant local service delivery effort.

12. There is an inadequate relationship between public education agencies and human resources agencies at the state level -

Over the past several years nearly two dozen states have created "umbrella agencies" which have brought together mental health, health, rehabilitation, social services and other human services agencies under a common bureaucratic format. In no instance is public education included in

these umbrella agencies. The net effect can be to make one of the largest enterprises of need to the handicapped individual more remote from the health and other human resources programs. It is important in each state to develop and maintain an adequate planning, coordination and evaluation linkage between education and other human service programs at the state level. The situation may be particularly acute in states where state education agency directors are elected and other state agency officials are appointed. Oftentimes this situation results in differing political backgrounds and constituencies which can work against effective inter-agency program planning and program development, especially between human resources and education. This type of partisan and unnecessarily differentiated agency activity should be circumvented where possible.

Crosscutting programs such as Offices for Children, Departments of Administration, Legislative Analysis Units, and others can be initiated in order to soften the effect of the remoteness often found between education and other state agencies around the country.

13. Education represents the greatest investment of resources -

Despite the fact that education represents the greatest investment of resources and perhaps is of the greatest developmental benefit for the handicapped, documentation and research from the field have been relatively sparse when compared with other areas of service affecting the handicapped, e.g., vocational rehabilitation. However, because recent litigation and legislation are highlighting the educational needs of the handicapped, it is likely that the quantity and quality of documentation in this field will dramatically increase. This along with a national commitment to provide full educational opportunities for all handicapped children by 1980 demands more information than currently exists. Consequently, the need for educational research, development and dissemination (now at an all-time low ebb) is greater than ever. Personnel and funds for field-based research on practical educational problems should be developed at the federal and state level. A minimum of 15% of the service delivery system budget should be earmarked for research, development and evaluation.

14. Lack of services to eligible persons -

There are currently numerous federal and state programs that are designed to serve the handicapped that are not fully enrolled. In some cases, only about 50% of those eligible for the programs are being served. Such programs as Supplementary Security Income (SSI), Early Periodic Screening, Diagnosis and Treatment (EPSDT), and Vocational Rehabilitation for the severely handicapped are significantly under-utilized. This is primarily due to a lack of public awareness and aggressive outreach of these programs. It is also due to the fact that the programs are not currently prepared for full enrollments in terms of finances, manpower, and organization.

Service providers must be reorganized and prepared to enroll and service eligibles. Services need to be promoted through public awareness campaigns. To cut costs, the red tape of screening must be reduced.

When new services are developed, they should be tied as closely as possible to generic services and combined in outreach, screening, and registration with other services directed toward the same populations.

The high cost of services, limited enrollments, service gaps, and lack of outreach is due to the fact that numerous services addressed to the handicapped are administered out of separate agencies. For example, services such as screening, food supplements, day care, early education, parent counseling, and health care for handicapped infants and toddlers are often provided by social services, public health, education and private agencies. While each of these agencies may have an important role to play in the delivery and monitoring of services, the duplication of administrative costs and the gaps and duplications of services must be reduced.

Counties and other local districts must develop single "ports of entry" where all service entry points can be found and administrative costs are shared. This would assure cooperation and coordination of service providers, increased public awareness, and reduce the need to search for services.

Single agencies should become responsible for the administrative costs, supervision, and coordination of services for different age levels. For example, public health from pregnancy to age five, public schools from age five to sixteen, vocational education and rehabilitation from age sixteen to twenty-one, social services from age twenty-one up, etc.

15. Expensive service delivery models -

Many of the models of service delivery for the handicapped were developed with short-sighted intentions and under unique service situations. Because of this, many of the service models now in use have become extremely expensive, e.g., institutional care and self-contained educational classrooms. Less expensive models to deliver better quality service must be utilized, e.g., handicapped children removed from self-contained classrooms to regular classrooms with resource support.

The long-run cost/benefit of service models must be determined and projected so that models employed will be cost beneficial in the future. For example, developing 50 to 100 bed facilities to replace large institutions may be cost/effective now, but over the long run may produce the high costs of our current outmoded institutions. Solutions closer to the mainstream of life are less likely to continue to require special costs over the long run, e.g., special transportation.

16. Lack of adequately trained personnel -

Services for the handicapped, more than ever before, require personnel who are both generalists and specialists at the same time. Service delivery personnel need to know their specialty. They also need transdisciplinary training in order to respond to the handicapped on a variety of dimensions and to know when to access other specialists. Current personnel do not often provide the services needed and too often access expensive, specialized services when not needed. Personnel planning services face the same dilemma--their specialized knowledge actually limits their usefulness. Manpower trained in a variety of human services areas (public health, education and social service planning) are needed to adequately plan the coordination of comprehensive services rather than to continue the current uncoordinated, categorical services.

Intense in-service training in transdisciplinary decision-making for key service personnel and human service systems for planners is desperately needed. Regional pre-service, in-service, and technical assistance systems are needed to provide the continuing education that key service personnel need.

17. High overhead costs of federal and state programs -

Federal and state program costs have shown a demonstrative and significant increase in the last few decades. This is largely due to the confusing and mixing of planning, decision-making, administering, monitoring, evaluation, reporting, and service delivery costs.

The federal and state agencies should contract for services delivered, thus retaining only the planning and monitoring costs and cutting the overhead costs of direct service delivery.

Federal and state government should provide block grants to private and public agencies closer to the service level. These grants should be provided with carefully defined standards of service but with limited specifications of methods of service to be used. Federal and state government should get out of the business of providing direct services.

FUTURES

It should be evident from this paper that the major need today is orchestration, consolidation, integration and the improvement of the quality and effectiveness of the activities we now have. Therefore, a major emphasis on bold new thrusts and directions is not here recommended.

There are a few innovative, new directions suggestions that should be mentioned.

1. There is a need for expanding and decentralizing our policy development and program evaluation process. The development and implementation of policies and procedures related to the implementation of effective services for the handicapped has been for too long centralized and isolated from the main body of the service enterprise. Regional and local policy development activities need to be mounted in order to improve the quality and quantity of direct services to handicapped individuals.

2. We still work largely without a comprehensive data base of information necessary for effective planning, resource development, client tracking systems and monitoring procedures. Without the rapid development of a comprehensive and shared information and data base, no national network of services can be effectively developed or evaluated.

3. The clear need for continuing support of service program activities begs for the establishment of regional and local technical assistance, evaluation, staff training and management programs. Unless the service machine is continuously oiled and adjusted, it will soon become obsolete and sputter to a non-productive halt. Technical assistance organizations, both public and private, should be continued and expanded with the major focus directed toward the development and maintenance of effective service programs.

4. The integration of services and the coordination of planning and program activities has been recited before. However, new models of coordination, collaboration, and integration of services should be developed from a basic and applied research effort. Funds should be made available to engage in organizational research and development activities to improve our continuing attempts to maintain effective, coordinated and integrated service systems.

5. We have yet to fully mount a preventive services program which would include health, economic, educational and social services. Fundamental and long range answer to the problem of handicapping conditions is to prevent their occurrence in the first place. Comprehensive research, development, training and demonstration services need to be developed in the area of prevention.

6. Finally, a continuing and escalated effort must be maintained in the area of advocacy on behalf of handicapped individuals and the modification of public attitudes toward the handicapped and their place in our society. The deviancy model is still too widely held. Evaluation is still conducted toward exclusion rather than inclusion. The focus on employability and a productive slot in the corporate state still overshadows the equally, and perhaps more important goal of improving human development and the quality of life for the handicapped person.

ISSUES

SPC III-1 How can we assure the delivery of quality services to handicapped individuals at the local level?

SPC III-2 How can we maximize the impact of research to improve service delivery?

SPC III-3 How can we establish adequate training programs, accreditation and licensing of service delivery personnel?

SPC III-4 How can we state commitment laws be written to maximize deinstitutionalization?

SPC III-5 What role should advocacy organizations play in service delivery?

SPC III-6 What is the validity of umbrella agencies in service delivery?

SPC III-7 How can we get consumers involved in federal, state and local goal-setting, implementation and evaluation?

SPC III-8 How do we accomplish joint evaluation, as it pertains to service delivery, involving the service provider and the consumer in fostering accountability in administration, decision making processes and outcomes?

SPC III-9 How do we assure goal setting in rehabilitation and long term care?

SPC III-10 How can existing Federal programs be consolidated, or modified, so as to use savings in tax monies previously required for the development of human resources on a more efficient basis?

SPECIAL CONCERNS

Summary and Issues on

CIVIL RIGHTS

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IV. CIVIL RIGHTS OF THE HANDICAPPED

SUMMARY OF AWARENESS PAPER

Human and Civil Rights of All Persons

It would appear from the basic principles and documents upon which this nation is founded that all citizens are presumed equal in that they share a common humanity and a common set of needs.* Therefore, all citizens are equal when it comes to having rights. A review of past and current treatment of handicapped individuals by all branches of government at all levels has, however, revealed an apparent utter disregard or distortion of these basic principles.

Overview of Unequal Treatment

A benign or indifferent policy of discrimination resulting in total or partial isolation and even extermination has generally characterized the treatment of persons with physical and mental disabilities in the United States. Indifferent, patronizing, and even hostile attitudes of American society's decision-makers have been responsible for a "crazy-quilt" pattern in the status of handicapped individuals in the American legal system. The 1970's have produced an increased effort by handicapped persons to assure their fundamental rights. These efforts have affected the legislative, executive, and judicial branches of government. In fact, it is becoming clear that the rise in litigation has influenced the actions of the other two branches. Inspired and encouraged by the consciousness--raising activities of other minorities and groups, handicapped individuals or their advocates have initiated litigation to erradicate discrimination in education, employment, free-and-ready access to public buildings, privately owned public accommodations, and all forms of public transportation systems; the right to residential and treatment services in a minimally restrictive environment; freedom from confinement in the absence of proper commitment procedures; freedom from restrictive zoning ordinances; right to vote; the right to marry, procreate, and adopt children.

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* On the International level, the United Nations General Assembly on December 9, 1975, adopted THE DECLARATION ON THE RIGHTS OF DISABLED PERSONS.

Handicapped Individuals: A Suspect Class Entitled To Equal Protection of the Laws

There is growing evidence to support the argument that handicapped individuals meet the criteria necessary to compel the courts to apply a strict scrutiny to governmental classifications. Historically, most handicapped individuals have been persons who had no access to the political process, who have been stigmatized as a legally sanctioned classification, and who have belonged to a class that is often congenital, essentially immutable, and over the existence of which its members have had no control.

Effective Enforcement and Implementation of Handicapped Individuals' Basic Civil and Personal Rights at the Federal and State Levels

New federal affirmative action and antidiscrimination prohibitions affecting employment and other areas of activity appear to offer much promise. The effectiveness of the enforcement of these provisions is the key to converting what have been considered as symbolic gestures into real laws "with teeth." The legislative history of Section 504 of the Rehabilition Act of 1973 shows that Congress intended that the section be enforced in a manner similar to Title VI of the 1964 Federal Civil Rights Act. Activists have advocated the inclusion of persons with physical and mental disabilities as a distinct group in Title VI and VII of the Federal Civil Rights Act, as amended, and the 1965 Voting Rights Act, as amended. This inclusion would equate the new antidiscrimination measures for handicapped individuals with similar efforts on behalf of other significant minorities. Since architectural, transportation, and communication barriers are significant impediments to the exercise of the right to vote by handicapped individuals, it is argued that voting rights and absentee ballot legislation on both the federal and state levels should be changed to authorize appropriate modification of polling places, registration, and absentee ballot processes.

In the overall attack on discrimination, it would appear useful to extend the jurisdiction of the Civil Rights Commission to reach persons with physical or mental disabilities in order to oversee and report on the federal enforcement effort. In the alternative, the Office of Handicapped Individuals, now in the Department of Health, Education, and Welfare, should be made an independent agency to accomplish the duties of the Civil Rights Commission with regard to handicapped individuals.

Section 504 can have widespread and pervasive influence on the status and treatment of handicapped individuals. When HEW, along with other Federal agencies, issues the proposed Section 504 regulations, they hopefully will reflect this expansive potential. Closely scrutinized should be the definitional aspects of "handicapped individual" and "otherwise qualified individual."

No person, including persons with physical or mental disabilities, either in the community or institutionalized in any way, should be deprived of the right to exercise constitutional and statutory rights belonging to all persons unless there has been a due process adjudication of such persons incompetence. The effect of this would be to require a review of all federal and state law (statues and court decisions) to erradicate any discriminatory treatment of handicapped individuals. Persons with physical or mental disabilities could not then be deprived of the right to manage their own affairs, to contract, to hold professional, occupational, or vehicle driver's licenses, to make a will, to marry, to hold or convey property, to vote in local, state, or federal elections solely by reason of admission or commitments to a facility or institution except where there has been an adjudication that such a person is incompetent or a conservator or guardian has been appointed for such person. In that event the handicapped individual's civil rights should be limited only to the extent of the appointed person's specific adjudicated responsibility. Contracts for specific services in return for a voluntary restriction on rights is a new, more flexible approach to guardianship.

Some state and local legislators and administrative agencies now allow handicapped individuals, like blind persons, who cannot drive to obtain identification plates which would be similar to driver's licenses. Such identification allows the person so afflicted to cash checks.

Architectural, Transportation, and Communications Accessibility

The right of access to publicly owned or financed buildings, publicly used but privately owned buildings, public streets and sidewalks and public transportation facilities and rolling stock has not yet been recognized as necessary and proper means or accommodations to the exercise of a person's political, economic, and personal rights. Architectural barrier statutes of some states and localities have been extended to cover not only public buildings but also most privately owned and publicly used buildings encompassed under the

jurisdiction of the building code. This expansion brings into coverage such places as hotels, restaurants, and apartment houses. Statutes prohibiting denial of access to public accommodations should, it can be argued, equate the accessibility that they mandate the meeting of an architectural, transportation, and communication barrier-free requirement. The building and renovation of public buildings which are inaccessible should be considered unconstitutional. Handicapped individuals and their advocates proclaim that federal, state, and local statutes banning inaccessibility of public buildings should be not mere symbolic provisions but mandating adequate enforcement mechanisms.

Right To Equal Educational Opportunity

The right to education of persons with handicaps has been recognized to consist of the right to participate in the process of obtaining knowledge and information necessary to cope with one's life situation. There should be no handicapped children excluded from a free public education (zero-reject education). Every special educational placement, denial of placement, and transfer should be preceded by constitutionally adequate due process protection. Individualized programs suited to the needs and designed to maximize the capabilities of each child should be developed. There should be a periodic review of the adequacy of the individualized program plan. A single agency should oversee the insuring of education programs for all children. Special education programs should be provided in the least restrictive and de-normalizing environment possible so that each child is educated in a setting as close to the normal classroom as is possible. (Compare Cascade System.)

Due process protection should protect the right to be free from inappropriate educational classification labeling and placement. There is often a stigma involved in labeling a person "handicapped" or "mentally retarded." A person has a right to placement in an educational program appropriate to his needs, abilities, and functional level. The use of culturally based intelligence tests resulting in the misclassification and inappropriate educational placement of numbers of minority groups should be periodically evaluated.

Right To Treatment In A Minimally Restrictive Environment

Federal and state laws recognizing the right to treatment and protection of the personal and civil rights of individuals who are institutionalized are being enacted and, hopefully, will be adequately

enforced. Examples of this are state and federal statutes enacting a Bill of Rights for mentally retarded, developmentally disabled, and hospitalized persons. The right to treatment encompasses an individualized treatment program designed to maximize the abilities which are administered in a physically and psychologically humane environment and supervised by an adequate and qualified staff in the least restrictive manner possible,

There is often a conflict between the constitutional right of handicapped persons to live in community-based facilities with several non-related individuals and restrictive zoning ordinances. State and local legislative bodies should address this problem.

In the right to be free from unconstitutional commitment practices, the issues involved include (1) lack of due process procedures in commitment statutes, (2) requirement of proof of dangerousness beyond a reasonable doubt on the basis of an overt act before a person can be involuntarily committed, (3) requirement of individualized treatment plan and investigation of less restrictive alternatives as prerequisites to commitment, (4) inability of parents to consent to the "voluntary" commitment of their children to a residential institution, (5) states may not incarcerate individuals for an indefinite period of time unless such individuals have been convicted of a crime or have been properly committed through constitutionally adequate procedures.

Right To Equal Employment Opportunity and Just Payment for Labor

The right to equal employment opportunities and to be free from peonage means that laws or regulations requiring institutionalized persons to work without pay or for an amount less than the minimum wage applicable to others should be unconstitutional in the absence of some overriding public interest. The enforcement of the Fair Labor Standards Act and the denial of Social Security and other work benefits should be reappraised.

Legal and Other Advocacy Activities of and for Handicapped Individuals

Client assistance programs in the rehabilitation process should be continued and expanded. Persons receiving rehabilitation services should play a more involved role in the decision-making in his or her case. Under new federal legislation, such as the Rehabilitation Act of 1973 and the Developmental Disabilities Assistance and Bill of Rights Act of 1975, legal and other advocacy programs of and for disabled persons will be broadened.

Right To Equal Access To Medical Services

The right of equal access to adequate medical services involves such issues as (1) the illegality and unconstitutionality of refusal to provide medical services to a handicapped person in a situation where such services would be available to a "normal person," (2) the inability of parents and guardians to refuse consent to lifesaving medical services for their children, (3) the duty of physicians and hospitals to provide medical treatment in emergency situations.

The Right To Live and Be Abroad In The Land

Jacobus tenBroek focused-in on the central principles -- the right to live with dignity and to be "abroad in the land," which is essential to personality, social existence, and economic opportunity. The deaf, the blind, the orthopedically disabled, the wheelchair user -- the developmentally disabled have the same rights as others do -- the right to privacy, the right to rent a house or an apartment, public or private housing, the right to live in and to determine their living arrangements and the conduct of their lives; the right to select their mates, raise their children, conduct businesses and commercial intercourse and expect due protection in the safe and secure exercise of these rights.

Simple justice warrants no less.

ISSUES

SPC IV-1 How can federal, state, local anti-discrimination laws and affirmative action be most effectively enforced?

SPC IV-2 What role can handicapped people play in legal advocacy?

SPC IV-3 How can we enforce the right to an equal education opportunity for handicapped citizens?

SPC IV-4 How can we enforce the right for equal employment opportunity for handicapped citizens?

SPC IV-5 What are the ways to accommodate the needs of institutionalized persons for occupations in light of the court ruling that these persons cannot work unless paid?

SPC IV-6 How can we implement the right to equal access to buildings and transportation systems for handicapped persons at the federal, state and local levels.

SPC IV-7 What should the right to treatment in the least restricted environment encompass and how can it best be enforced?

SPC IV-8 What can be done to insure that handicapped people can exercise their right to vote?

SPC IV-9 What must be done to insure that handicapped persons can marry, procreate and rear both natural and adopted children?

SPC IV-10 What can be done to insure that handicapped people are knowledgeable of their rights?

SPC IV-11 How do we insure the full enforcement of the present legislation and how do we close the existing loopholes?

SPECIAL CONCERNS

Summary and Issues on

UNIQUE PROBLEMS OF HANDICAPPED MINORITIES

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V. UNIQUE PROBLEMS OF HANDICAPPED MINORITIES

Introduction

While it is true that handicapped individuals who are members of racial and ethnic minorities suffer the same indignities as other handicapped individuals, there are special and unique problems that these individuals face because of the lack of awareness of their cultural differences. In addition, prejudice and racial discrimination continue to exclude a great number of minorities from full participation in all aspects of society. However, there are no statistics to indicate the number of handicapped individuals within this special population.

These factors tend to place handicapped minorities at an increased disadvantages compared to other handicapped individuals. This paper discusses the unique problems of the following ethnic minority groups in our society; Asian Americans, Black Americans, Native Americans, and those with Spanish Surnames. It is, therefore, divided into four sections.

SECTION I

UNIQUE PROBLEMS OF HANDICAPPED ASIAN AMERICANS

Physical and mental disabilities affect Asian Americans in a manner not unlike other citizens and residents of the nation. Handicaps of every variety are experienced within the population. Asian Americans are, however, differentiated by their particular cultural backgrounds and history, as well as their degree of participation in the service delivery systems that have traditionally responded to the needs of the handicapped. This paper shall attempt to provide highlights of the major distinguishing factors of the Asian American handicapped populations as compared to other miniority populations.

The presentation of any topic related to Asian Americans is intrinsically complex and incomplete. The designation, Asian American, has a current and evolving definition that responds to the dynamic condition of numerous ethnic communities that modify the definition. In California, where a third of the total population of Asian Americans residing on the mainland United States concentrate, the term may include fifteen or more culturally, ethnically and linguistically distinct communities. The problem of adequate presentation is further complicated by the inadequacy of existing data collection and retrieval systems, which fail to segregate or collect data on Asian American populations. This situation is a significant symptom of the Asian American dilemma, as the invisibility of the population may typify the degree of interest and concern for serving this population.

Asian Americans

The multi-ethnic term, Asian American, is generally inclusive of populations from Asian nations. More recently, practice has included Pacific Island populations such as Hawaiian, Tongan, Samoan and Guamanian. While the initial rationale for these populations to join together reflected an objective to achieve greater visibility, the term, too often, has merely been a substitution for persons, who could not be designated as White, Black, Native American or Spanish Surname. Asian Americans share a number of common experiences. The majority population has historically and currently viewed them as a monolithic group. This tendency is manifested in the muddled transference of particular stereotypes for a particular ethnic group inappropriately from one ethnic group to another. Stereotypes or images of more visible Asian American groups, such as the Chinese or Japanese, are very often mixed and undifferentiated. Therefore, Asian Americans are perhaps, the least acknowledged of the national minorities.

The approximate number of two million Asian Americans in this country represent a hundred year plus history of immigration and resettlement in the United States. Early Chinese and Japanese immigrants came to American shores, arriving with the belief that America afforded them the opportunity to better their lot. The early experience contains a theme of exploitation and maltreatment, which included exclusion from citizenship, exclusion from land ownership, exclusion from particular employment, segregation in schools. The discrimination against early Asian immigrants was codified in over 600 laws that were directly focused to discriminate against them. In this hostile environment early colonies of Asian Americans began developing internal devices to provide for the welfare of the group. Based upon family, church, prefectural or fraternal relationships, the ethnic communities developed alternative institutions that paralleled the functions of existing majority culture institutions. The development of these institutional structures as a basis of survival significantly affects the structure of service delivery systems that would, today, seek to outreach to Asian Americans. These institutions reflected the mistrust that the communities developed for public institutions.

Succeeding generations and subsequent Asian immigrant waves, such as the Filipino and Korean groups, inherited this experience of mistrust. The incarceration of 110,000 Japanese Americans, most of whom were citizens of the United States, during the Second World War greatly reinforced a condition where Asian Americans subtly accepted and recognized a status as second class citizens. The analogy of an unwelcome guest residing within the domain of a hostile host, reflected the situation of Asian Americans. Consequently, Asian communities adopted a strategy of accommodation toward the dominant host culture.

The effect of an attitude of accommodation toward the host culture created a mixed reaction. The overtly negative stereotypes of the communities became modified to the extent that Asian Americans became viewed as a "model minority." Accommodation developed into a community characteristic that sought to be as unobtrusive as possible, and in that manner avoiding the displeasure of the host culture. In effect, much of the energy of Asian American communities was directed toward becoming non-threatening and invisible. One aspect of this effort to achieve invisibility is represented in a dominant concern within the ethnic communities to shed themselves of as many vestiges of racial, ethnic, cultural or social differences as possible. This phenomenon eventually carries over to a developed characteristic behavior that promoted the active denial of deviance within the ethnic community. Acknowledgement of deviance or social problems in this setting

would endanger the invisibility that the community sought, and would detract from the model minority image that was presented. The operation of these dynamics in the ethnic community coupled with a generalized mistrust of public service delivery systems, operate to impair any realistic visibility of human needs outside of the ethnic community.

Within the ethnic communities, the alternative institutions that existed, operated on relatively meager resources. From a cultural value perspective, consumers of these services would be bound by a culturally reinforced reticience to utilize these services. Haji (Japanese for shame) would tend to affect the individual and the family because of the stigma attached to the family's inability to resolve the situation. Additionally, culturally based requirements for politeness, would place immediate hesitations on an individual or family to impose upon their cultural institutions, knowing that the resources of the institution would be sparse. Under these internal conditions, handicapped persons within Asian ethnic communities, usually lived in neglect and isolation.

Service Delivery Barriers

The history and cultural values of Asian Americans in the context of their settlement in the United States provides major barriers to service for the handicapped in these communities. The individual and family, the ethnic community, and the dominant society all maintain mutually reinforcing barriers to service. Cultural hesitation, family shame and disability act as barriers on the individual to find means of remediation or rehabilitation of their condition. The development of alternative institutions, community attitudes, community image and community self image interfere with the development of service delivery systems appropriate to Asian American handicapped persons. The invisibility of the needs of ethnic handicapped, the inability to respond to cultural and linguistic needs of the ethnic handicapped, and fear and mistrust by ethnic consumers, act as barriers for Governmental and other major service delivery agents to interface with Asian ethnic communities.

The net result of these factors is that no organized effort to address the unique needs of Asian American handicapped persons was developed until very recent times. Two projects related to the handicapped individuals in the Asian American community began in the Los Angeles area one year apart. In 1971, the Oriental Service Center allowed its Program Development Specialist to initiate efforts toward the development of a sheltered workshop facility that could serve a predominant Asian American clientele. A year later, the Japanese Community Pioneer Center supported a Japanese American Sightless Institute

Project that was funded initially through Social Rehabilitation Service, Department of Health, Education and Welfare. The first efforts to reach Asian American handicapped develops more than 150 years after they began arriving on American shores. The experience of these two entities remains the only basis from which any current insight on handicapped Asian Americans can be found. Conveniently, the sheltered workshop incorporated as a separate entity under the name, Asian Rehabilitation Services, and the Japanese American Sightless Institute joined the former agency in early 1975. The following sequence of service delivery concerns represents perspectives derived from the two interrelated projects.

Population Identification

Because of the historical lack of service delivery to handicapped Asian Americans there has developed an assumption within the target group that there is little alternative to the neglected and isolated existence that they experience. The social deprivation of this experience adds to the negative self image of the population and, in effect, prevents the affirmation of efforts to be open to change. Additionally, many handicapped persons experience a long term existence under the protective atmosphere of a highly structured role in the family. New experiences for this population are highly threatening, as appropriate role responses are not structured for the handicapped, as they would be in the existing family setting.

In responding to this situation, an obvious need for community education and community validation of the effort is required, before handicapped persons within the ethnic community can be identified. As the Asian American communities tend to be institutional rather than geographic, the existing community institutions are major targets for re-education and validation. The re-education process for the ethnic community is critical in that community institutions, in large part, affect family attitudes toward allowing and seeking services for family members.

Potential service delivery consumers are more likely to seek services with family originated support and validation. Equally significant is the users understanding of eligibility requirements, as ambiguity on eligibility may be understood by the potential service user as a potential conflict situation. Conflict situations are likely to be avoided by Asian American handicapped persons.

The experience both of Asian Rehabilitation Services and Japanese American Sightless Institute, has been the identification of high anxiety of new clients. This anxiety is somewhat reduced if the

initial contact remains within a community setting that contains elements that are familiar to the person. Bilingual literature, bilingual staffing, respect for culturally familiar protocols and like features greatly enhance the ability of both referral and direct service agencies to attract Asian American service users.

A complicating caveat in implementing a target group outreach effort is the variance in organization of particular ethnic communities. Generational variables, degree of newness to the country or community, population numbers, geography and culture are considerations that must be assessed for different ethnic communities and for different community settings around the country.

Target Characteristics

Handicapped Asian Americans reflect their population as a whole. Demographic detail will be comparable to the general ethnic population with which the person identifies. However, the historical neglect and reticence to receive service may reflect a greater severity of impairment in the client population. Historically, Asian Americans have developed a mistrust for public service delivery agents. Cultural values tend to restrict the utilization of internal community resouces. Together, these two factors tend to discourage service delivery utilization unless no options are available. Under these conditions, a significant portion of the service applicant population is likely to have fairly great service needs at enrollment. This dynamic in the Asian American population is common in other human service delivery systems. Paralleling this characteristic, may be accompanying feelings of shame and guilt for having the need for service, and much anxiety regarding confronting an unfamiliar situation. Anxiety levels may vary depending upon the degree of familiarity and trust that the service provider can demonstrate to the new client. In general, Asian Americans tend to develop trust more easily within a setting that is culturally and ethnically familiar. Conversely, they are apt to feel greater shame in that same setting, assuming a shared value with the service provider of the same ethnicity.

To illustrate the degree of anxiety and apprehension that Asian Americans have toward public service delivery agents, the entire Japanese American Sightless Institute participant population made known their intention to resign from activity in the project when the California Department of Rehabilitation insisted that the participants would necessarily have to become concurrent clients of the Department. Participants resumed project activity only after assurances that they would not be forced to enter the State's caseload. The participants in this project had individual experience or heard stories of negative experiences within the state system. The mutual sharing of these

"horror stories" was enough to prevent any of these participants from considering utilizing state services. Only after several arranged interactions with state staff, did the anxiety of the participants relax sufficiently enough to have a few persons attempt to investigate state services.

Summary

Asian Americans are in the peculiar position of having experienced a history that has resulted in the development of individual and community values and attitudes that are often incongruent with the service delivery vehicles that exist in the public sector. Until very recently, the invisibility of the needs of handicapped Asian Americans concealed the incongruency of the delivery system. The development of two projects in Los Angeles to provide an interface, bridging the gaps between the handicapped person and the ethnic community, and the ethnic community and public service deliverers, will probably encourage the development of similar efforts elsewhere. Such efforts will be necessary if Asian Americans are to be provided equal opportunities to develop full potential.

SECTION II

UNIQUE PROBLEMS OF THE BLACK HANDICAPPED

It is well known that to be black already places the nonhandicapped individual in a disadvantaged position.

Blacks have, on the average, to overperform in order to have access to reasonable jobs. They have fewer educational opportunities, lower incomes and live their lives in hostile environments, largely as a result of the impact of racism.

To be handicapped in addition to being Black, most frequently places upon an individual an almost insurmountable burden which results in his or her being set aside from the mainstream of everyday life as the white majority knows it. The nature of the handicap that a Black may have is of minor importance, compared to the unwillingness of society to accept the responsibility for seeing to it that he or she is fully integrated into community life. The problem of the Black who is handicapped is indeed complex, not only does he or she have to live with an excessive economic burden, but in addition, education is frequently not available to him or her. Their access to the community facilities, their home, stores, schools, and transportation can only be achieved through use of extreme measures and then with the involvement of at least another person.

If for example, he or she is blind, frequently no training has been provided to this Black even to permit restricted mobility, without the aid of another.

If he or she is physically disabled, the barriers to access to all types of physical facilities both within the home and in the community are so great that many individuals do not get out of their living quarters for long periods.

The Black handicapped individual lives in constant fear of his environment, where every minor obstruction assumes major importance and amplifies his or her disability and development.

The magnitude of the Black handicapped individual's problems are so vast that it defies reasonable description by this writer. However, I have attempted to highlight five major areas of concern below. While all these areas interact in a complex manner to confound and prevent the development of a measure of independence for the Black handicapped, I have attempted to comment briefly on each one separately below. These five major areas are as follows:

1. Economic problems
2. Sociocultural problems
3. Educational problems
4. Environmental problems
5. Communication problems

Sociocultural

The major problem here is acceptability of the handicapped Black as a totally integrated part of the community. Handicapped children that are Black are deprived of involvement in the community more frequently than others because the family is so involved in working to survive, that the amount of time available to the child is very restricted.

The adult handicapped Black is frequently unable to become totally integrated into community life because his range of mobility in the community is restricted. The community labels him as inferior and does not provide for his free access to education or ways for him to develop socially and culturally.

Educational

The Black family, the Black community, and the handicapped individual have the least understanding about their rights to work, education, and the availability of assistance for education about the disabled. As a result, many Black handicapped children are labeled and treated as "cast-outs".

Schools attended by Blacks at all levels from elementary school through colleges and universities are not equipped to provide for the handicapped. Educational opportunities for Blacks are restricted even for the most handicapped individual. Most Black families are ill-equipped and are not provided with the education and information needed to cope with and understand the problems and needs of handicapped individuals.

Many handicapped individuals, therefore, make false assumptions about their own "net worth" through lack of education. For Blacks who grow up with a handicap, the odds of acquiring an education at the college level and beyond practically does not exist. Many such individuals still believe that they are to spend their lives in back rooms or selling pencils.

Environmental

The worst environment for normal life is the one in which most Blacks must live. This is mainly a function of their low economic status and sociocultural disfranchisement. Thus, the average handicapped Black lives his life in a community that is the least barrier free. Most of the public buildings, schools, including predominantly Black universities, which Blacks use most, are the least accessible to the handicapped.

Public transportation is not available to the physically handicapped that use wheelchairs and crutches and the cost of special transportation is excessive.

Those few facilities that are available to the handicapped are frequently set apart so that the individual has to be treated as a special case.

Communication Problem

Although there is a vast amount of information available pertaining to all facets of the handicapped individual's problems and technology exists for coping with many of these problems, hardly any of this information gets to the Black family and the handicapped individual within that family.

It is said that Blacks are unaware of "How to Work the System" so that they might reap its benefits. Few Blacks understand that it is the right of the handicapped child, for instance, to receive an education that is commensurate with his capabilities.

Few Blacks that are blind know how to read Braille and that they have a right to know, few Blacks can understand sign language, and so on we might go listing items of this kind. The adequate communication of information to members of the Black community is significantly enhanced by their lower economic status.

Economic Problems

The major problem facing the handicapped Black and his or her family is economic. Since most Blacks have low incomes and are just barely able to survive, the impact of the introduction into the family unit of a handicapped individual presents a formidable problem.

The high cost of care and for the provision of aids to assist the disabled individual to gain any degree of independence frequently cannot be afforded. This creates the necessity for a greater degree of personal assistance to the handicapped family member. This takes time away from the family that could normally be used for wage earning.

The cost of higher education of the handicapped is prohibitive, so that the handicapped children of Blacks are automatically unable to acquire any education commensurate with their potential. Few handicapped Blacks are seen in regular secondary schools and even fewer advance to the college level.

The Black adult who becomes handicapped frequently finds that his job is not accessible to him or her, especially if it is in a Black establishment where the barriers to access are the most numerous. If this individual, of course, is the head of a household, then the entire economic structure of the family is destroyed.

Summary

1. Black handicapped individuals want to be an integral part of the family, home/community and social order, yet frequently at present, they are not.

2. Black handicapped individuals do not want to be abandoned, nor socially isolated or insulated in some special place or some attic of the house, yet frequently at present they are.

3. Black handicapped individuals need and want empathy. When the handicapped is separated from his or her family and/or community they become "emotional orphans".

4. Black handicapped individuals need security. Currently, many live with no hope and in fear and without the possibility for either gainful employment, educational advancement or cultural development.

5. The Black handicapped individual wants to be loved, wanted and useful to their family, friends and society.

SECTION III

UNIQUE PROBLEMS OF HANDICAPPED NATIVE AMERICANS

Introduction

Statement of the Problem

Any position paper which purports to address itself to conditions affecting the "Native American" population must begin with a definition of what constitutes a "Native American", how the definition is arrived at, and the limitations of such a definition.

For purposes of this paper, Native Americans are considered to be those persons of Indian, Eskimo, or Aleut descent who are eligible for services provided by the Indian Health Service; this definition limits the population to some 500,000 persons residing in 26 States on Federally recognized reservations or in Alaskan villages. Another 500,000 persons live in urban areas at the present time and, for purposes of the paper, have generally lost their Indian "identity" by virtue of their place of residence. An undetermined number of other persons of Indian descent, who reside on State reservations and are, therefore, not Federal beneficiaries, are also not included in this report.

Discussion of Problem

Two major problems drastically limit the scope of the paper. The first is that comprehensive data on all handicapping conditions simply do not exist since the Indian Health Service does not now keep statistics on the number of persons with conditions considered handicapping. Many Indian children who are handicapped are cared for by State Crippled Children Services but States may vary greatly in determining what conditions they consider to be handicapping. Mental retardation and severe behavioral disorders are not included in State Crippled Children's programs; learning disabilities are usually excluded from State programs and even deafness is not considered handicapping in some States when it comes to determining whether or not the State can provide a hearing aid for a deaf child. Degree of impairment and disability need to be considered in determining an individual's inclusion on a list of the handicapped, but none of the information which follows gives such a breakdown. These estimates are largely based upon previously presented testimony to Congress, State Crippled Children registries, Head Start enrollment data, numbers of institutionalized children, and hospital admissions.

A second limiting factor in determining the extent of handicapping conditions is the tendency among many Indian communities to absorb the handicapped, or other "different", person within the structure of the society. Many Indian communities are characterized by very extended family relationships so that the handicapped person can be cared for within the family or within the community at large. Estimates of the number of deaf Navajos, for instance, have been extremely hard to come by since many Navajo persons are known to be deaf who spend their lifetimes herding sheep, a vocation which they are capable of pursuing and which has a great deal of value within the Navajo community. While there are Navajo children enrolled in various State schools for the deaf, the means for determining what proportion of those actually needing special education cannot be arrived at. As might be inferred from the foregoing, the acceptance of "deviance" is higher among many Indian groups than the contemporary American society as a whole. In some groups, for example, the child born with a handicap is not evaluated negatively since it is assumed the child has the prenatal choice of how he wishes to be born and, if handicapped, is so by choice. Some Indian languages also show a great deal of sophistication in recognition of the problem. The Ute term n'kvat ("can't hear so can't talk") is much more highly descriptive of the condition than are the corresponding English terms "deaf and dumb". In common with other tribal characteristics reflected in language the Ute term implies no value judgment of the condition. While there seems to be little question that the person with a severe handicap is recognized as being different in the Indian communities, by in large such difference is accepted within a wide range of tolerance. By contrast, prosthetic devices do not seem to have the same acceptance in some Indian communities. While perhaps a reflection of childhood generally, anecdotal accounts of Indian children ridiculed for wearing either eyeglasses or a hearing aid are rather abundant. Ridicule does not seem to be associated with the condition requiring the prosthetic device, however.

In writing of given groups of persons, recognition of and attitudes toward handicapping conditions the risk towards over generalization needs to be avoided. There seems to be a tendency in much of the literature to generalize the "Indians" as if they were a very homogeneous group of people, particularly with respect to attitudes, mores, religious beliefs, and attitudes. In fact, variations of attitudes and beliefs are as common among Indian communities as any other segments of society. Sapir (1951), as mentioned below, was an early observer of a particular segment of Indian societies' attitudes towards disfiguring or handicapping conditions. More recently, Bergman (1968) has noted in Navajo boarding schools the activities of Navajo children which would not seem to fit the generalized position stated above:

Group hostility is often directed at scapegoats. In a situation where large groups of children are constantly together with rigid but not very close adult supervision, opportunities for teasing are particularly great. I regularly see depressed, masochistic children who have a special proclivity for being baited, and the baiting is often extreme. Children with physical deformities are also often badly treated by their classmates, and there is little the out numbered dormitory staff can do about it.

Children with seizures are in an even worse position. Seizures are cause for alarm and disgust among traditional Navajos. They are thought to be caused by incest or haunting by the dead, and are sometimes taken as a sign that the affected person is a witch. Children with seizures are usually stigmatized and ostracized, but they can and often do strike back. Many of them learn that the attacks frighten the other children so much that they can be used as a weapon. They then develop a large stock of pseudoseizures with which they can sometimes dominate the life of their dormitory. I once attended a conference about one girl, who besides her grand mal seizures, which were well documented clinically, had other attacks which the school called "her running seizures." When aggravated, she would begin to yell and run madly about the room. When she did, the other sixty girls in the dormitory would all run out the doors. I asked the dormitory attendants what they did, and one answered, "We hide in the closet."

In summary, the following are particularly significant problems in determining the extent of handicapping conditions affecting American Indians and Alaskan Natives:

1. lack of information sources reporting on handicapping conditions;

2. lack of definition of the extent of what constitutes "a handicap" in the cross-cultural sense. From the foregoing, it seems apparent that "handicap" is a highly variable term meaning different things to persons within different cultures. This is particularly a problem in providing services to Indian beneficiaries if, as in the instance cited above, a child "wanted to be born" with a cleft palate. People in this group would appear to be less likely to consider such a child "handicapped" although the prevailing non-Indian community surrounding this reservation would certainly view the child this way when he entered public school. As also mentioned above, the

Navajo child wearing a hearing aid may be more likely the considered "deviant" by virtue of the prosthesis then on the basis of the handicapping condition.

Behavioral-Emotional Disorders

Bryde (1967) reported that for the Oglala Sioux in South Dakota a 60% school drop-out rate between grades 8 and 12 was an indication of poor mental health. In his research he compared Oglala Sioux students with non-Indian students and found significantly greater personality disruptions on the part of the Indian students on such variables as rejection, depression, anxiety, withdrawal tendencies along with social, self, and emotional alienation. Bergman (1968) points out one of the major reasons for such disruption as it affects Navajo children when he notes that the Navajo child coming into an English speaking environment is analagous to anyone of us suddenly being enrolled in an astronomy class at Moscow University and being expected to learn classes taught in Russian. Bergman elaborates on the problem as it affects educational achievement:

> In the world of the boarding school not only the Navajo language but almost all things Navajo are rated very low. The children are frequently told not to be like their parents and are often admonished against following the traditions of their people. One middle-aged woman told me that she went to school in the days when few Indian children were enrolled and she went more or less against the wishes of her parents. She had been eager to go to school and did well in her first two years, but then left suddenly. I don't believe that the school knew the reason for her leaving but she told it to me. Her teacher one day was angry at the laziness of the class and said, "If you want to live in a hogan for the rest of your life just don't bother to study". Since this woman definitely did want to live in a hogan for the rest of her life, she left school. There are other bizarre consequences of this system. In my consultations with school personnel I often encounter instructional aides who pretend not to speak Navajo. They have become so convinced that speaking Navajo is a bad thing to do, that they often won't admit that they can. The children learn that what they say in Navajo is effectively kept secret from the authorities even if one of the Navajo-speaking members of the staff hears them, because the Navajo staff member will be too ashamed of having understood to tell anyone.

The effects of such an environment on the child obviously interfere with more than his educational achievement. Bergman further describes the resultant hostility which evolves and at the same time provides some insights into how certain handicapping conditions are viewed from the traditional Navajo point of view.

From Alaska, Nachmann (1969), describes what she calls "the main types of non-physical interferences in learning the intellectual development which hamper the Native student":

1. Lack of early stimulus to learning: "The pre-school years for the largest and most crucial intellectual development takes place are years of extreme stimulus deprivation for many Native children. The climate precludes outdoor play for a large portion of the year. The out of doors in the Artic provides a highly simplified sensory environment. The average home is a meagerly furnished one or two room structure, largely devoid of toys, books, pictures, musical instruments, indeed most of the sensory input which stimulates the urban childs' development." (P.498)

2. Interference in character development: "Prolonged or repeated separation from parents (due to hospitalizations of parents or children, removal of children to boarding schools, and other kinds of family disruptions) remain a common occurrence for Alaskan families." (P.499)

3. Interference in development of capacity to sublimate: "The use of the intellect, if it is to preceed at all beyond simple note learning, depends upon their having occurred in childhood the development of this capacity to transform the basic instinctual energies into intellectual ones...it is difficult to provide the necessary conditions for this development in a crowded one room house where the sexual activity and the destructive violence that life entails must be viewed at close range by every member of the household." (P.533)

4. Separation of education from other meaningful experiences: "There exist for many children not only the temporal discontinuities in personal relationships mentioned above, but also a sharp discontinuity between schooling and other meaningful experiences." (P.533)

5. Teacher-student attitudes which inhibit learning: "Because of its linguistic and cultural strangeness participation in the classroom routine is experienced by many children here as exposure to criticism and to the danger of being found wanting--the aim becomes to conceal ignorance and to avoid embarrasement by saying as little as possible and keeping uninvolved. School becomes a continuously defensive ordeal to be survived". (P.499)

6. Perpetuation of gaps in basic skills: "Through the wide spread practice of 'social promotion'...children who have failed to acquire the basic language and arithmetic skills upon which all subsequent learning is dependent or pushed along through the grades according to age rather than achievement. As a consequence what is taught becomes increasingly unmeaningful, and the entire educational process increasing an empty compliance with a ritual requirement". (P.499)

7. Lack of supervisory aid for teachers: "The lack of intensive local supervision and the disadvantages of 'absentee administration' is a problem which stems from Alaskas' immense distances and which education hence shares with many other occupations. Teachers are frequently new to Alaska, new to the ways of life in the remote north, and new to teaching at once. They are cut off from the means to professional stimulation and development which are available elsewhere". (P.500)

Nachmann recommends that handicapping emotional and mental conditions resulting from these problems could be changed within the educational system through recognition of the undereducation of the Native as a universal problem, through elimination of social promotion, through recognition of pre-school and adult education are essential to the success of the regular school program, the bilingual Indian and Eskimo teachers and aids be trained and used, and that higher trained supervision and in-service training be provided on the local level.

Also specifically to Alaska, Fleshman (1969, P. 529-531) notes that the Alaskan Native child suffers an excessive amount of illness to the extent that roughly 15% of such children are hospitalized each year. He observes that there

are two major effects on the children, the first is direct and related to disease and the second is indirect and related to non-specific factors such as separation from parents and prolonged hospitalization. In the latter case, particularly, significant emotional problems can result when we see that many Native children have become ill in the village, must be taken to the field hospital and then are often transferred up to 600 miles to a referral hospital where they may spend several months and then return home. He states that a number of such children who as infants were separated from their parents were, at about 10 to 12 years of age, having difficulty in relating to their families, were failing in school, and were also failing to grow in normal physical fashion even though separation may have resulted from a parent who was ill rather than the child.

Other socio-cultural factors relating to handicapping conditions in Alaska include mental retardation, which is difficult to determine since no one has yet devised a reliable test that excludes sociologic factors. Such factors combined with infectious diseases such as meningitis lead Fleshman to conclude that probably every Alaskan village will contain at least two school age children who are mentally retarded. He concludes (P. 530-531): "The diseases that we are dealing with are essentially unmanageable by traditional medical means. They disappeared as killers and cripplers many years ago in the rest of the United States, yielding to correction of the environmental factors responsible such as housing, sanitation, nutrition, and education. I feel that it is imperative that the education system consider the tremendous gap that exists between the Alaskan Native pupils and the average child in the United States and to realize that poorly nourished, physically handicapped or chronically ill children cannot learn nor achieve in a competitive society. The curriculum must contain a much stronger emphasis than it now does on learning about sanitation, nutrition, basic, and, especially, reproductive physiology until the time these children are able to accept and utilize the contents of the traditional United Stated curriculum."

Historical Perspective

The extent of handicapping conditions in previous times and their prevalence among American Indian groups can only be surmised. One way of determining whether or not such conditions existed is to determine from the native language whether or not words in that language exist for a particular problem. Again, very few linguists have written on this matter nor, to the writer's knowledge, has anyone interested in handicapping conditions investigated the linguistics literature to determine the existence of such conditions. One

notable exception to this was the work done by Sapir (1915) whose study of "abnormal speech in Nootka" developed the interesting thesis that certain consonants in the Nootka language had linguistic meaning and designated certain physical classes of persons such as unusually fat people, unusually short adults, those suffering from visual defects, hunchbacks, etc. Particularly prevalent were a wide variety of speech defects expressed through such "consonatal play". Other than these references, however, no other reference to handicapping conditions historically were located by this writer.

State of the Art

As can be inferred from the foregoing, the "art" of determining the extent and severity of handicapping conditions among the American Indian and Alaskan Native peoples is by all accounts extremely primitive at the present time. Existing health records are not designed to extract information regarding handicapping conditions per se nor is there a strong liklihood that such categories would be included in the near future. Other sources of information, such as State registers for handicapped children, vocational rehabilitation programs, and other sources from State and Federal agencies, are increasingly difficult to come by for a number of reasons such as the no racial identification of the handicapped person recorded, the Privacy Act, etc. Many Indian groups today are still very highly mobile and individual persons may seek out services from any number of different facilities within a large geographic area so that even if a handicapping condition were to be noted there is a liklihood that it would be recorded several times. This is further complicated by the tendancy among some Indian groups for persons to change their names with some regularity so that even reliable census figures are not obtainable at the present time in many of the locales served by Indian Health Service. "State of the art" at this time is a rather vague concept in the context of the needs of this White House Conference.

ADDENDUM

Probably the most pressing general need insofar as handicapping conditions among Indian persons is concerned is the same problem that faces delivery of health services generally. The average Indian income is still in the neightborhood of $2,000 a year, unemployment averages 40% overall and the 500,000 Federally recognized Indians (representing over 260 tribes and 215 Alaskan Native villages) are spread very thinly over 26 States whose Indian populations vary from over 435 in Lousiana to 180,000 in Oklahoma. Partly due to these conditions, many diseases of potentially handicapping effect are extremely prevalent in the Indian populations; tuberculosis, for example, is 6.5 times higher than the rate for all of the citizens of the United States. The increased prevalence of ear disease has already been mentioned. Not included in the present report, however, had been such other factors as the extremely high rate of persons crippled in automobile and other accidents, effects of other debilitating diseases that are not seen elsewhere in the United States (such as trachoma), and the whole gamut of conditions arising from poor nutrition, etc.

With respect to the concerns of this Conference, the primary need for assessment of handicapping conditions, persons affected by these conditions, services available, and services needed must first start with developing cross cultural definitions of what constitutes a handicap, how persons with handicapping conditions can be located in view of some of the problems mentioned above, determining which of these conditions might eventually be preventable and an assessment of rehabilitation program needs of those whom the condition already exists.

SECTION IV

UNIQUE PROBLEMS OF HANDICAPPED INDIVIDUALS WITH SPANISH SURNAMES

Introduction

This paper intends to deal with the concerns of the Spanish speaking Americans and particularly with those within that community who experience handicaps. An effort will be made to present material that will be helpful in understanding this group of people, and to examine issues relative to the service delivery systems intended to meet their needs. There will be an attempt to describe the Spanish speaking population, including: an assessment of their numbers, their mode of entry, their relative position in this society, and the causes of their disproportionate socio/economic problems. An effort will also be made to illustrate the unique cultural differences that have an impact upon the therapeutic or rehabilitation efforts made in their behalf. Finally to be considered are those issues involving the effectiveness or ineffectiveness of the socio/medical/educational/ rehabilitation systems that have been established to serve the needs of the handicapped. This will include alternative strategies or approaches that merit examination/implementation/evaluation.

It is still recognized that the number of Spanish speaking persons in the United States comprises a substantial population, enough to form the fourth largest Spanish speaking country in the Americas after Mexico, Argentina, and Columbia. While historically they have been identified with the southwest, they are also found in significant numbers throughout the U.S. They represent 17 percent of the population of California, 30 percent of New Mexico, 20 percent of Colorado and great numbers in other states such as Washington, Michigan, Illinois, Kansas, and Iowa. The Los Angeles area has approximately 1.5 million persons of Spanish speaking descent, making it one of the largest Spanish speaking cities in the world (Burns, 1972). There are approximately 3.5 million persons of Puerto Rican descent, and one million of these reside in New York, and there are great populations in New Jersey, Massachusetts, Pennsylvania, and Florida, as well as many states throughout the nation. Persons from virtually every Spanish speaking country can be found in the United States. These include the Cubans in Dade County, Florida and persons from other Carribbean, Central, and South American countries.

All Spanish speaking people have concerns as an ethnic group in the United States, and these express themselves symptomatically in personal/socio/economic areas. Unfortunately, a large number (25 percent) are below the poverty level, 15 percent are unemployed and the dropout rate from school ranges from 50 to 80 percent with educational under-achievement being a universal concern (Padilla and Ruiz, 1973). As with other poor people, there is a high level of health problems and these are compounded by problems of malnutrition, industrial accidents, congenital defects, etc. Therefore, a higher incidence of handicapping conditions can be expected. These problems are then again compounded by a lack of resources to intervene in these conditions. There is also the problem of a lack of responsiveness by social/medical/manpower/educational/rehabilitation delivery systems.

Cultural Shock and Social Services

Ethnic minorities share in the right to have their values and ways of life respected and incorporated into institutional and social service programs - rehabilitation services being only one of the multi-faceted services available in our communities. No man develops by himself, rather he is a product of the socialization and enculturation. Inherent is the understanding that there are significant differences in the ways cultural groups define problems, participate in planning interventions, and utilize systems available to deal with problems that may arise. The individual must be viewed from a vantage point that incorporates the client's values, family structure and community matrix and not merely the medical aspects of the disability. The challenge then for those working with the Spanish disabled is to give consideration to the distinctive socio-cultural attributes within the client's community matrix.

Physical and mental disabilities are a part of life, yet their psychological consequences are monumental. The individual experiences a sense of powerlessness and loneliness, avoidance and denial, hostility and anger. The physical trauma of loss generates a series of phenomena-denial and isolation, anger and hostility, depression and resolution - which demands a process of adjustment by the individual. Though change is a characteristic of life, in the dominant society's view, change involves mastery and control over the environment in a manner that subsumes achievement.

The adaptive style of the individual is directly related to the degree to which the individual ascribes to a particular set of cultural characteristics. The systematic body of learned characteristics, which are transmitted from parent to child, can be regarded as being on a continuum; that is a flow binding one generation to another. Thus, members from a Spanish speaking cultural experience and percepttion have a greater likelihood of ascribing to these behavioral characteristics than their Anglo counterparts (Murillo, 1971). The behaviors noted along the continuum range from a more traditional to an assimilative perspective. Often in clinical settings, evaluations are based in terms of the Spanish speaking individual's degree of adjustment to the majority culture. It is well to note that the same behaviors have different meanings for different cultural groups.

Deviance from the expected norm does not necessarily denote pathology, but rather reflects a dynamic process in which members are continually adjusting their patterns of living and ways of coping. The primary goal of the counselor thus is to assist the handicapped or disabled individual in achieving a lifestyle which is satisfying and congruent with his self-perception.

Cultural perspectives do influence the adaptive process; in this case, defined as the dynamic process of reciprocal interaction between man and his environment, to achieve a sense of equilibrium. The Spanish speaking individual, who is psychologically prone to accept support and cooperation, finds himself in conflict when placed in a treatment plan that emphasizes self-reliance and individualism. Generally solutions to problems are sought within the extended family rather than from alien institutions. The Spanish speaking community provides an avenue for acceptance by altering the expectations and roles for the individual in accord with his abilities and capabilities. The individual's status, acceptance, and prestige is still based on the handicapped/disabled individual's ability to assume those altered roles and responsibilities which contribute toward the common good of the household. Though his accommodation retains the individual's dignity, status and prestige, it may deter from that individual's utilization of services. The potential fear of being lost, or disregarded by social/medical/rehabilitation service agencies, overrides the necessity of those services.

In contrast, the individual's acceptance in the dominant society is related to or measured by the individual's ability to succeed and climb the ladder of success. Emphasis is given to individualistic, aggressive, and competitive roles in both seeking assistance from social service agencies and in cooperating with the treatment of

rehabilitative plan. Institutions often define the client's ability to relate successfully with the particular agency in terms of "motivation."

In addition to the complementary role conflict, the Spanish speaking individual finds that the clinical agencies are often unable to meet the client at the level of his psychological readiness for interdependence, because the term denotes a negative rather than a positive connotation. Interdependence can be viewed as a tool for growth from which the individual emerges with the skills and tools to achieve a lifestyle that is satisfying and congruent with his self perception.

One major point this paper has continually attempted to make clear is this: the Spanish speaking people have been barred from an active role in the administration of the helping services designed to alleviate their disadvantaged socio-economic position. Because little input has been allowed from this group, they have been disenfranchised from the decision-making processes that govern their lives. They have suffered from a lack of responsiveness to their unique cultural characteristics, which has been symptomatic of the service organizations created to serve the handicapped individuals of our society. It has been established that the environment in which they exist, which can justly be described as colonialism, has been the major cause generally of their disadvantaged socio-economic position.

This is the vicious cycle of poverty. If we are to enable these people to share in the services provided for them, alternative strategies must be examined. The consideration and possible acceptance of these new directions is more than a challenge; it is, and must be, a legitimate public issue.

Therefore, sheer economics support the need for responsive service and make is feasible to create separate programs for each ethnic group. It would seem that, where there is a critical need to justify it, community based programs should be preferred, and that under such conditions a separatist strategy would be a rational choice. Its strength is that it places responsibility and accountability closer to the client and, therefore, closer to the problems. Further, it permits self-determination and decreases the dependence upon external administration, which has often been insensitive or paternalistic.

A serious effort is required to eliminate the artificial barriers that have kept them out. The selection criteria for positions in those agencies serving the handicapped must reflect and accept the cultural characteristics of all applicants. This strategy may be described as one of cultural pluralism. Its consideration is a major issue; it has neither been accepted nor practiced before. It is also a strategy which will be welcomed by the Spanish speaking community.

ISSUES

UNIQUE PROBLEMS OF HANDICAPPED MINORITIES

SPC V-1 How can we assure services to handicapped Asian-Americans, Blacks, Native Americans, and those with Spanish surnames that is responsive to their cultural differences?

SPC V-2 How can we incorporate cultural awareness training into the already existing training programs to providers of services to handicapped individuals?

SPC V-3 How can the negative attitudes of minorities and toward minorities be altered so that services to handicapped individuals of these special populations are more successful?

SPC V-4 What research mechanisms should be made available so that minority handicapped individuals can be identified and served?

SPC V-5 What can be done to eliminate communication and language barriers in public information programming that hinder the provision of successful services to handicapped minorities?

SPC V-6 What systems can be established to insure an ongoing evaluation of services to minority handicaps?

SPECIAL CONCERNS

Summary and Issues on

UNIQUE PROBLEMS OF DISABLED VETERANS

Awareness Paper Prepared By

James A. Maye
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VI. UNIQUE PROBLEMS OF DISABLED VETERANS

SUMMARY OF AWARENESS PAPER

Introduction

The purpose of this paper is to incite discussion and further research into the unique problems of disabled veterans. Generally speaking, one could initially assess the problems facing the disabled veteran and the civilian disabled as being the same. In part, this is true, for such things as architectural barriers, social attitudes, and scientific technology affect all similar types of disability groups equally. Usage of the term "unique" in dealing with veteran's problems can be justified in two general areas: (1) Because the Federal and state governments have established a separate system with specific methods to deal with disabled veterans, the effects of these programs, both good and bad, are unique to the veteran population; (2) When the disabled veteran population is viewed collectively, certain problems have significantly different occurrences than are found in the civilian disabled population. These problems are considered to be unique to disabled veterans and will be the subjects of discussion of this background paper.

The scope of this paper will be limited to those areas considered to be of a problem nature to the disabled veteran and unique because of the manner in which it is dealt with or because of the nature of the group in which the problem occurs.

A Profile of the Veteran Population

The population of veterans in this country accounts for one of our largest minorities. The 1975 V.A. census indicated that there are 29,294,000 veterans, of which 26,194,000 have had some period of wartime service. The number of disabled veterans totaled 3,226,296 and was composed of 2,220,169 with service connected disabilities and 1,006,127 with non-service connected wartime disabilities. It should be noted that there are no statistics on the number of non-service connected peace-time disabilities because the Veterans Administration does not have access to information on disabilities unless a claim for V.A. benefits is filed. No monetary benefit programs are available for this category.

In the category of non-service connected wartime, it is somewhat difficult to ascertain the severity of disabilities and it is not

wise to place very much faith in these figures as being representative of the actual number of veterans with disabilities. The reason for this is that a financial need criterion is placed upon eligibility for receipt of any benefits and the records reflect only those persons in receipt of pensions from the V.A. Conversely, the V.A. places no financial need requirement upon the service connected veteran, for his benefits are a payment of due compensation for losses incurred in line of duty. Furthermore, in the case of the service connected veteran, the V.A. medical review rates the degree of disability. The rating scale is from 0% to 100% in ten percent increments. The degrees of impairment and the percentages of service connected veterans with those degrees of impairment are shown in the following table.

	Number	Percent of Total
No disability	28,765	1.3
10%	867,866	39.1
20%	344,756	15.5
30%	315,208	14.2
40%	180,626	8.1
50%	112,573	5.1
60%	117,217	5.3
70%	78,394	3.5
80%	38,154	1.7
90%	13,215	0.6
100%	123,395	5.6
Total	2,220,169	100.0

It is also interesting to note that 422,536 of the service connected veterans are from the Viet Nam Era. The number of non-service connected wartime veterans from the Viet Nam Era is 7,299.

Profile of the "Typical" Veteran

In order to support the premise of the unique nature of veterans' problems, it is necessary to determine how the "typical" veteran differs from his non-veteran contemporaries.

1. A combination of stringent medical screening prior to entry into the military service, the provision of excellent health care by the Armed Services, and the active physical nature of the military life style results in an individual physically stronger and healthier than the national average.

2. The ratio of males to females among veterans is drastically

different from the civilian sector. In 1975 there were a total of 562,000 female veterans in the United States, or approximately 1.3% of the total veteran population.

3. The mean average education of the veteran population is 12.6 years; it is 12.3 years for the non-veteran male population.

4. The mean average income for veterans is $11,360 per year; for non-veterans, it is $7,430 per year.

5. The unemployment rate for veterans in 1975 was 4.7%, while for non-veterans it was 8.3%.

The profile developed from the above statistics shows the typical veteran to be a male, most probably the head of a household, above average in health, annual income, employment, and slightly better educated than his contemporaries. It would be reasonable to assume that in the case of the disabled veteran, this profile would be similar if it were not for the intervention of his disability.

Profile of a Disabled Veteran

Examination of statistics concerning disabled veterans reveals the following:

1. Health variable, from good to poor with the probable average just below that of the general population.

2. The ratio of males to females among the disabled veteran population is even greater than for the overall veteran population. Less than 0.5% of disabled veterans are female.*

3. The average educational level of disabled veterans is comparable to that of the total veteran population at 12.6 years.

4. The mean average income would seem to be substantially below that of the average veteran, although this cannot be completely substantiated. A survey of spinal cord injured veterans indicated an annual income of approximately $7,200 per year.

5. Unemployment for the disabled veteran is significantly

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* Estimate based on V.A. figures and polls of several veterans' organizations including Paralyzed Veterans of America, Blinded Veterans and Disabled American Veterans.

greater than for the total veteran population and than the non-veteran able-bodied population. The unemployment percentages vary with the categories of disability. The HumRRo report indicated percentages as low as 8% for the college graduate with a minor disability and as high as 30% for the high school dropout with a severe disability. Other statistics provided by the Paralyzed Veterans of America indicate that unemployment among paralyzed veterans is as high as 87%.

Thus, the profile of the "typical" disabled veteran is that of a male of less than average health, having a high school diploma, earning less than his physically fit veteran contemporaries and slightly less than the average non-veteran male, and having moderate to severe difficulty in finding employment.

The Unique Areas

It is necessary to make a distinction between the different groups of disabled veterans. In order to see how the problems of the disabled veterans are uniquely different from the problems of the disabled civilian population. The group having the fewest number of differences in problems when compared to the civilian disabled would be the non-service connected peacetime veteran, followed by the non-service connected wartime veteran, and finally the service connected veteran, who shows the greatest variance in problem areas.

Both non-service and service connected veterans differ from their civilian counterparts in the following ways:

1. Extremely high ratio of males to females.

2. The availability of separate medical facilities in Veterans Administration Hospitals at no cost to the veteran.

3. Certain educational benefits such as the G.I. Bill.

4. Eligibility for membership in certain veterans' organizations which can assist him in receiving his lawful veteran's benefits.

5. Nearly all are in the age groups which are normally employed.

The non-service connected wartime veteran has, in addition to the above, other available programs:

1. The availability of a Veteran's Pension Program which is based on financial need. This income supplement is designed to provide those with the greatest need a modest financial base on which to live. As their income increases, the financial assistance diminishes proportionally.

2. In conjunction with the Pension Program, certain limited medications and prosthetics are available to the non-service connected wartime veteran, provided his income does not exceed a certain level.

Program differences and also variances in group profile are most evident when the service connected veteran is compared with the civilian sector of the disabled population:

1. The service connected veteran is more likely to have enjoyed excellent physical health prior to a sudden and traumatic onset of his disability. There will be an exclusion of such factors as serious congenital defects, crippling childhood diseases, and disorders related to aging.

2. The effects of the disability create situations in which the individual is mandatorally removed from his job and his life style, i.e., the military service. In all cases he must find re-employment and a new life style. Although this may be true in the civilian sector, in many cases the disabled individual can and does return to the same job or to the same type of work.

3. The service delivery systems for veterans programs work both for and against disabled veterans. For example, both state and local programs for the disabled encourage if not require the disabled veteran to utilize his V.A. benefits before he is eligible for their programs. The Veterans Administration provides for such services as physical restoration, rehabilitation, and education to disabled veterans but it does not operate its own program for job placement. The veteran is usually left to seek such services from other agencies or to find employment on his own. The HumRRo study indicated that 70% of the veterans in their study had to seek employment without assistance. Ineffectual programs in veterans employment do a major disservice to him. One Labor Department program is reported to have placed only 22.7% of the two million veterans who sought its services. Only half of those two million veterans received any reportable service at all. Only 16.7% of the disabled veterans seeking assistance were employed.[13] This differs from the services

provided by the various states' Departments of Vocational Rehabilitation where the policy is to assist the individual through the entire physical restoration, training, job placement, and follow up which insures readjustment by the client.

For all practical purposes, the disabled service connected veteran can be viewed as having the same potentials as those characteristics given for all veterans, but investigation bears out the supposition that most disabled veterans are underemployed relative to their capabilities and in comparison to their able-bodied counterparts.

There are still other areas of special concern which affect the veteran differently from the non-veteran. Some of these, such as public attitudes towards veterans of the Viet Nam Era are difficult to document. However, without doubt, many of these veterans suffer additional prejudices because of their participation in an unpopular war, misconceptions of war atrocities, and the prevalent use of drugs. These have created problems which are unique to Viet Nam Era veterans.

Conclusions and Recommendations

Certain data have been presented in this paper to support the supposition that disabled veterans as a group are unique in certain circumstances, and that problems arising from these situations are peculiar to that specific group. As a result of the research for this paper, five significant problem areas unique to disabled veterans became apparent:

Problem I: In the case of the veteran with the service connected disability, current military procedures necessitate the abrupt conclusion to his employment and retraining and relocation under a new employer. This is true for all cases of service connected veterans. The disabled civilian may have the opportunity to return to the same employer, either through modification of his old job or through a change of position after retraining.

Problem II: Veterans with non-service connected disabilities who qualify with wartime service are penalized when they return to gainful employment by having their meager veteran's pension and medical and prosthetic benefits drastically reduced or more probably stopped. Such negative incentives cannot help but influence the seriously disabled veteran who already has mental reservations about his ability to function in a competitive setting to avoid the risk of giving up the limited security of a guaranteed pension for a job which he may not be able to perform. With the exception of welfare programs, the civilian does not face this degree of negative incentive.

Problem III: Certain problems are inherent in the programs set up for disabled veterans by the Federal Government. Although these problems are numerous, one is of paramount importance. The rehabilitative service offered by the Veterans Administration includes physical restoration, provision of basic prosthetics, retraining, and possible provision of limited tools for employment, but no job placement service or vocational follow-up is offered which can be comparable to those services offered by the State Vocational Rehabilitation Programs. The veteran is left on his own to locate and contact other appropriate Federal agencies responsible for assisting him with employment. The result is very poor coordination between agencies who are supposed to work together for the total rehabilitation effort. Those agencies charged with the duties of finding employment for the veteran fail to do an adequate job. The greater percentage of disabled veterans are left to find employment without any agency assistance. The lack of follow-up procedures further complicates situations because programs can seldom be evaluated for proficiency or effectiveness.

Problem IV: In many states and localities there are regulations which restrict dual eligibility for rehabilitation benefits. The disabled veteran is restricted from utilizing state and local programs which may be superior to Federal benefits until those Federal benefits have expired or have been exhausted. Without question, having access to two different programs is much better than having access to only one as is the case for the civilian disabled, but a unique problem develops for the veteran in that cooperative agreements between separate Federal and State or local programs seldom occur and the veteran is not counseled as to the comparative value of different programs. The result is a loss of energy, time, and money, while the veteran tries to make an educated guess as to the appropriate course of action.

Problem V: An unusual turn of events in our history of national policy has created a nationwide review of ethics. The intervention of the United States in the internal affairs of Viet Nam caused great social upheaval in America and without doubt the Viet Nam Era veteran has suffered from the stigma attached to that war. For veterans who became disabled in that conflict, an added barrier comes between him and the general public. It is a well accepted fact that the public has emotional reservations about dealing with any physically, emotionally, or mentally impaired individual. So the Viet Nam Era disabled veteran has even more prejudices to overcome, because of the time and place in which he became disabled.

Recommendations

It is the recommendation of this paper that a more in-depth study to be undertaken to identify other problems which are unique to the disabled veteran population. They must be identified in order to initiate a plan of action for their resolution and to bring the goal of total rehabilitation one step closer.

A second recommendation is that because of the generally good educational, financial, and organizational levels which disabled veterans have already attained, the resources which they can contribute must be utilized more fully in order to benefit all disabled individuals. The White House Conference on Handicapped Individuals and other civilian disability groups should begin investigation into areas of similar interests and needs and develop programs in cooperation with and with the assistance of veterans groups such as the Disabled American Veterans, the Blinded Veterans Association, and the Paralyzed Veterans of America.

ISSUES

SPC VI-1 What methods can be established within the Veterans Administration to insure ongoing evaluation of services?

SPC VI-2 What measures must be taken to insure that proximity, need and quality of medical services for veterans match those of the private sector?

SPC VI-3 How can job placement of disabled veterans be improved and integrated into existing job placement systems?

SPC VI-4 How can disincentives to work be eliminated for the disabled veteran?

SPC VI-5 How can the Veterans Administration insure that disabled veterans are aware of all services and benefits?

SPC VI-6 What measures are necessary to insure comprehensive counseling services for disabled veterans?

SPC VI-7 How can coordination of all Federal and State services to disabled veterans be established?

SPC VI-8 What measures are required to improve the image of disabled veterans?

SPC VI-9 How can the Veterans Administration improve coordination of research with other public and private endeavors?

SPC VI-10 How can existing legislation related to employment of disabled veterans be disseminated and implemented?

SPC VI-11 What steps can be taken to retain disabled uniformed military personnel, where feasible, in military service rather than referring such individuals to the Veterans Administration or returning them to civilian life?

SPECIAL CONCERNS

Summary and Issues on

UNIQUE PROBLEMS OF THE HANDICAPPED AGING

Awareness Paper Prepared By

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VII. UNIQUE PROBLEMS OF THE HANDICAPPED AGING

SUMMARY OF AWARENESS PAPER

Introduction

This paper is addressed to the public policy issues facing the handicapped elderly. This group of the elderly is a minority within the population of the American elderly - a minority within a minority. The field of aging is briefly reviewed and the place of the handicapped elderly within the field is assessed. In particular, the treatment of the handicapped elderly in the Older Americans Act, and under Social Security, is appraised and recommendations are developed for legislative action, designed to maintain the income of this elderly population and assure them the defined coverage in all programs serving the elderly, especially in areas of income, health and housing.

The multi-dimensional and peculiar problems of the elderly handicapped relate to inequitable treatment of this group within the provisions of the Federal Housing Act; the implementation of health programs under the Social Security Act, (Medicare and Medicaid) and the structuring of major Federal income maintenance programs benefiting the elderly; the transportation programs of the Urban Mass Transportation Act; and the major training and research programs designed to provide manpower in the field of aging; major employment programs benefiting the elderly under various legislative actions such as the Domestic Volunteer Service Act and the Comprehensive Employment and Training Act. Although the legislation for many programs tends to refer to the "aged and the handicapped", the handicapped aged do not receive fair recognition in legislative programs or in the delivery of services. Federal programs do not discriminate between the elderly (able-bodied) and the handicapped elderly, because legislation for the care of the elderly has not attempted to isolate the special problems within the elderly population which require special attention.

The Growth of the Aged and the Handicapped Aged in the Population

There is a general consensus that old age is the last stage of human development, but there is little agreement as to the exact age at which this final stage begins, or the actual physical signs that indicate its onset. This creates problems for legislative programs dealing with the elderly.

Although there are biological, psychological and social definitions of aging, statistical demarcations of old age have been adopted by the United States and other nations. According to statistical definition, certain ages have been selected as those at which old age begins for purposes of retirement and pensions.

In the United States, age sixty-five (65) has been selected as the age of retirement. Therefore, "Older Americans" refers to any American at 65 years of age or above, and age 65 is defined as the age of eligibility for full Social Security benefits. However, many older Americans are now electing to retire at sixty-two (62) with reduced benefits under provisions provided by the Amendments to the Social Security Act.

Only in the last few decades has the attention of the United States Government been directed toward the social, economic, political and scientific problems associated with the aged segment of the American population. Increased interest and concern is due to the fact that handicapped older Americans are becoming an increasingly large part of our population.

There are figures to indicate the growth of the handicapped aged in view of the fact that this population comprises approximately thirty-five percent (35%) of the elderly population. Increases in birth rates between the 1800's and 1920's, Post World War I flood of immigrants and advances in medical science contributed to the growth in number of this group of elderly in the United States. On the basis of the death rates in 1973, average life expectancy at birth was seventy-one point three (71.3) years for Americans.

In view of the fact that public policy does not pay attention to this group of special minority, official statistics, for example, are classified into the "aged, the blind, and the disabled". This classification is a demonstration of the official inability to distinguish between the aged in general and the approximately one-third (1/3) that is handicapped, and, therefore, the failure to address programs and projects to the special needs of the impaired elderly.

Disabilities of various forms are part of new roles which some older people are likely to experience. The various degrees of disabilities produce varying degrees of incapacitation and dependency. It is estimated that about thirty-five percent (35%) of Americans aged 65 and over have some disability serious enough to limit their capacity to work, keep house or engage in other major activities. The importance of aging to the handicapped is the fact that as age increases, the probability of disease, illness, or disability increases.

The Place of the Handicapped Elderly in Federal Programs Benefiting the Elderly

Historically, the impaired elderly have not been distinguished, either in law or in literature, from the rest of the elderly population. Researchers, as well as legislators, tend to ignore this subgroup of the elderly completely, or vaguely refer to the "aged and handicapped" citizens, generally. Although the probability of one form of handicap or the other increases with age, there are millions of aged Americans who are not handicapped. These able-bodied elderly take up more than their fair share in programs serving the elderly, compared to the impaired elderly.

Employment

The major employment programs benefiting the elderly include the following: Older Americans Community Employment Service Programs, Volunteers in Service to America (VISTA), Service Corp of Retired Executives and Retired Senior Volunteer Program. Apart from VISTA, under the provisions of the Domestic Volunteer Service Act of 1973, the major Federal employment programs benefiting the elderly do not carry any special consideration for the physically and mentally impaired elderly. These programs should be re-oriented to address themselves to the drastic problems of employment facing elderly handicapped persons.

Health Care

Maintenance of good physical and mental health is of major importance to all aging and aged Americans. However, many handicapped older Americans living on limited fixed incomes do not receive adequate medical care because of prohibitive medical costs and the lack of trained health personnel to serve them.

The 1971 White House Conference on Aging recommended that comprehensive health care should be available to all elderly Americans as a matter of right and entitlement. Health care for the aged should be an integral part of a coordinated system that provides a comprehensive delivery of health care services, including long-term care for the impaired elderly. The provisions of these legislative acts are so general that the handicapped who are in dire need of extra attention have not been provided for.

The elderly handicapped who are in need of nursing-home care face a variety of problems in the cost, quality and range of services available. Average nursing home charges are about six hundred dollars ($600) per month; while average social security benefits for a

retired couple are about three-hundred and twelve dollars ($312) per month. Limitations on Medicare coverage of such services often leave either the aged patient or the Medicaid Program (Title XIX of the Social Security Act) as the only source of payment. The developing trend toward reclassification of patients to lower levels of care (from skilled nursing-homes to homes providing less medical care), fostered by the requirements of the Social Security Amendments of 1972 (P.L. 92-603), may be resulting in patient transfers based on consideration of State costs rather than the patients' need for care. The lack of availability of suitable alternatives to long-term care, such as home health services, results in the handicapped elderly being institutionalized when they could be better cared for in their own homes.

Many bills have been introduced in Congress that would expand the Medicare Program, but they have not addressed the problem of making a distinction between the impaired elderly and the rest of the elderly population. A person who is aged and also impaired has special health problems which deserve special attention within already established health programs. The Program of Health Insurance for the Aged and Disabled (Medicare), under Title XVIII of the Social Security Act, is a program providing for persons who are aged or disabled, but no provision is made for the individual who is in double jeopardy of being aged and handicapped. This group of the elderly requires equitable treatment under the program: the dependence caused by age is aggravated by the special problems arising from incapacitation.

The Federal health care programs benefiting the elderly include health resources development construction and modernization of facilities, construction of nursing homes and intermediate care facilities, and grants to States for medical assistance programs (Medicaid). These programs are structured to meet the needs of the mainly able-bodied elderly, and if the impaired elderly are included in the implementation of these programs they will provide significant improvement in the lives of thousands of aging handicapped persons. The Comprehensive Employment and Training Act (CETA), 1973, funds can be used to expand the employment of the handicapped elderly. Special appropriations should be clearly designated for the handicapped, including the handicapped elderly.

Housing

Based on the 1970 Census, 3.8 million elderly households (head 65 and over) rented their residences in 1969. An estimated 2 million persons paid at least thirty-five percent (35%) of their income for rent. In 1970, over 6 million elderly homeowners paid an average of

eight point one percent (8.1%) of their income in property taxes. Households with incomes of less than $2,000 paid property taxes amounting to an average of sixteen point six percent (16.6%) of their incomes. Taxes were much higher (as high as 30%) in certain regions of the nation. The handicapped elderly constitute a significant number of the elderly homeowners. In 1974, the average homeowner (of all ages) paid about three point four percent (3.4%) of his income in property taxes.

There are housing programs designed for the elderly and the handicapped by the Federal government, but the lumping together of the elderly and the handicapped in the appropriation of funds for these housing projects creates a situation in which the double jeopardy of being elderly and handicapped is not addressed. There should be defined appropriations for the construction of housing units for the handicapped elderly. Such units should include space for "essential persons" looking after the handicapped: the present practice of dealing with housing units for the handicapped elderly within the general appropriations for the elderly does not go far enough in solving the problems of this special group.

Income Maintenance

The Federal Bureau of the Census reported that in 1974 the following proportion of unrelated individuals aged 65 and over were below the poverty level: 28.9% for whites, 60.5% for blacks, but 31.8% for all ethnic groups considered. For families of the elderly, 7.7% for whites, 27.7% for blacks and 9.5% for all races below the poverty level. For the handicapped elderly as a group, the income situation is worse. Their poor condition is the root of most complaints and dissatisfaction expressed by the aged in the United States. Income maintenance for the older Americans should not be studied and evaluated from only the racial point of view, but also from the point of view of the severity of their physical and mental conditions in old age. It is important that the income of the able-bodied elderly be compared with that of the impaired elderly in assessing the performance of Federal income maintenance programs for the elderly.

Legislative matters dealing with the income of the elderly requires a thorough study of the existing sources of income for the American elderly. The sources of income vary for different racial groups in the country, but Social Security remains the principal source of income. Attention should also consider the income problems of the impaired elderly. The Supplemental Security Income program should provide additional funds for the persons who are not only aged but also handicapped. Income derived from wages is the second most important source for older people and this is the source in which

the handicapped are least represented. The third ranking income source is income derived from assets in real estate interest, dividends and other investments. Public assistance is the fourth ranking income source for elderly people.

Search for Solutions

The 1971 White House Conference on Aging held Special Concerns Sessions on the handicapped aged. The purpose of these special sessions was to provide for in-depth discussion on special aspects of the circumstances of the older population of the blind, deaf and physically disabled.

The recommendations of the Conference for the blind included that the National Eye Institute be required to better statistics on incidence, prevalence, and etiology of blinding eye conditions; that Congress amend Titles XVIII and XIX of the Social Security Act to cover low vision aids when the need is certified by an ophthalmologist or an optometrist specializing in low vision treatment; and that the number of low vision centers be increased and staffed under the supervision of an ophthalmologist or a qualified optometrist. It was further recommended that the Administration and Congress develop a network of personal care benefits for individuals with a certain level of functional disability to enable the older person to purchase whatever services are necessary to help him remain in his own home, if he so wishes; such benefit is to be in addition to basic minimum income and assure a financial basis for local community service providers. For the deaf and physically handicapped, there are other recommendations for what Federal, State and local agencies should do to enhance their rehabilitation.

The problem with the treatment of handicapped elderly within the Federal and State aging programs is that the appropriation process does not designate specific funds for this group of older Americans. The advocacy groups of all races working for the aged paint the pictures of the handicapped elderly to push legislation through Congress. However, the legislation and Federal appropriations that result do not designate specific line items for the impaired elderly. The field of aging may not be short of ideas about what should be done for the handicapped elderly, but the aging programs and legislation at Federal and State levels do ignore this special group. Any action that would provide a better future for the impaired elderly within the aging programs should aim at carving out special defined appropriations for the handicapped elderly. The following recommendations should be of special interest to those who are working to make the existing Federal programs for the elderly more meaningful for the impaired elderly:

1. Handicapped persons with special skills irrespective of age should be allowed to remain actively employed without means test (retirement test) within the Social Security System.

2. An increased number of handicapped elderly should be considered for employment under Title IX of the Older Americans Act of 1965, and the Comprehensive Employment and Training Act, 1973. Provisions should be made in the Federal budget for direct appropriations for the handicapped elderly under these Acts.

3. The Supplemental Security Income Program (SSI) of the Social Security Act (Title XVI) should be amended to provide special income maintenance for any person who is both aged and handicapped.

4. Provisions should be made in the Housing Act of 1959, as amended (Section 202), and the Housing Act of 1949, as amended (Sections 521 and 525), to provide for direct appropriation for projects serving only the handicapped elderly.

5. Special legal services should be guaranteed to the mentally impaired elderly within the Older Americans Act. The legal problems of the mentally impaired elderly should be distinguished from those of other elderly.

6. The elaborate training provisions of Title IV of the Older Americans Act should be redesigned to provide specifically for the inclusion of facilities for students specializing in the problems of the handicapped elderly as part of multidisciplinary centers of gerontology, and personnel training.

A significant development favoring the handicapped elderly is the reference in the 1975 Federal Council on Aging, Annual Report to the President, to "frail elderly" defined as:

> ".... the elderly -- usually the oldest of the old -- who require support from society because of disabilities of increasing age"

The Report called for "some needed national actions" which would provide a national system of care for the group of elderly. It is premature to see this as a new awareness for special treatment of the handicapped, but it provides some satisfaction to know that certain persons are starting to speak out for this neglected segment of our population.

Summary

In spite of the lack of data available on the handicapped elderly, we have made an effort to provide quantitative information about this population group. Their place in Federal programs serving the elderly was reviewed and found to be minimal. It was maintained in all programs (health, housing, income maintenance and employment) that the handicapped are not appropriated their fair share. The impaired elderly are used by advocacy groups to convince law makers to approve funds, but in the final slicing of the cake the special needs of the handicapped elderly are not properly addressed. We referred briefly to the work of the 1971 White House Conference on Aging in the area of the handicapped elderly and stressed that the basic aging issue is not one of ideas about the needs of handicapped elderly but the translation of ideas into defined provisions in legislation and in the Federal budget without grouping them with all the rest of the able-bodied elderly population. Finally, we made a number of specific recommendations for amendments in the Social Security Act, the Housing Act, and the Older Americans Act to provide for defined coverage of the handicapped elderly.

ISSUES

SPC VII-1 What action can be taken to allow handicapped aged individuals to remain actively employed, if they so desire, without a means test within the Social Security System?

SPC VII-2 Given that employment for the aged is provided for under Title IX of the Older Americans Act and the Comprehensive Employment and Training Act, how can we assure that direct appropriations are set aside specifically for the handicapped elderly under these acts?

SPC VII-3 What kind of a special income maintenance could be provided for those individuals who are both aged and handicapped?

SPC VII-4 How do we assure that the special needs of aged handicapped individuals be provided for under the present Housing Acts?

SPC VII-5 How can differential appropriations necessitated by such special needs be supported and provided for by Federal, State and local governments?

SPC VII-6 How can we guarantee that special legal services be provided for all elderly persons who are mentally handicapped?

SPC VII-7 How can we assure that training programs for providers of services be redesigned to include specialization in the problems of the handicapped elderly?

SPC VII-8 In what ways can we make the public aware that there are special needs of the handicapped aged that are different from those aged individuals who are able-bodied?

SPC VII-9 What systems can be established to insure an ongoing evaluation of services to aging individuals who are handicapped?

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